SAVONIA
University of Applied Sciences

THESIS – MASTER'S DEGREE PROGRAMME
SOCIAL SERVICES, HEALTH AND SPORTS

THE CURRENT STATE OF FAMILY INTEGRATED CARE MODEL IN KUOPIO UNIVERSITY HOSPITAL NEONATAL INTENSIVE CARE UNIT

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THESIS
Abstract

Field of Study Social Services, Health and Sports			
Degree Programme Master's Degree Programme in Digital Health			
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Title of Thesis The current state of family integrated care model in Kuopio University Hospital Neonatal intensive care unit			
Date	12.11.2023	Pages/Number of appendices	90 / 9
Client Organisation Kuopio University Hospital, Neonatal Intensive Care Unit			

Parental involvement and family integrated care in the Neonatal Intensive Care Unit, NICU is seen as a key value in today’s neonatal intensive care. Family integrated care in the NICU promotes parental engagement and development of parent self-sufficiency. The purpose of this thesis was to study the current state of family integrated care and the use of the current printed discharge plan in KUH NICU. The goal of the thesis is that the results of the thesis research can be used in further development of a digital care path.

The thesis process followed service design methodology and double diamond model working process. The thesis research was done with qualitative approach using thematical interviews as a data collection method. Thematic interviews were carried out with one NICU family and six NICU nurses. Content analysis was made from NICU nurses’ interviews and the results from the NICU family interview were disclosed separately, as it was not enough to be generalised as a part of the content analysis.

According to the thesis research results, nurse led parental guidance and supportive NICU environment are the most important supportive factors of family integrated care (FICare) practices in KUH NICU. The main challenges affecting the FICare practices as described by nurses were related to busy work environment, lack of resources and occasional lack of systematicity when it comes to guiding the NICU parents during different parts of their care path. According to the results, the printed discharge plan material is not in systematic use at the moment in KUH NICU.

The research results describe the current care protocols in KUH NICU as told by NICU nurses. The results describe the well working policies and the challenges related to them. KUH NICU has great operation models and guidelines developed. However, not all seem to be implemented according to the protocol. The task of creating the digital care path for a prematurely born baby in KUH NICU using the service design model will be a goal for future projects. The thesis research results created a foundation for a future digital care path as a novel service model. However, the challenge for future research is to increase NICU parents to participate more actively in the future research and developmental projects, and therefore validate the results of this thesis research from parent perspective.

Keywords
digital technology, guidance, patient counselling, premature infants, qualitative research, telemedicine, service design

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1 INTRODUCTION

Globally, it is estimated that every year 15 million babies are born too early. This means more than one in ten babies are born before 37 weeks of gestational age. In Finland, about 5-6% of all babies are born prematurely before 37 weeks of gestational age, and the number of very preterm babies born is around 330 per year, being 1% of all newborns. (WHO 2018; Finnish Institute of Health and Welfare 2020.) Prematurely born babies need specialised care from the beginning of their lives.

Parental involvement and family integrated care in the Neonatal Intensive Care Unit (NICU) is seen as a key value in today’s neonatal intensive care. Family integrated care in the NICU promotes parental engagement and development of parent self-sufficiency. This type of care intends to guarantee families accessible, unbiased information concerning their baby and involves parents in the decision-making process during the hospitalisation period. The goal is to allow parents, as well as siblings, to have unlimited access to the unit, and to be bedside with their baby. (Banerjee, Aloysius, Platonos & Deierl 2017, 9.) Preterm babies have shown better wellbeing overall in neonatal intensive care units with family integrated care protocols compared to traditional care models. (Lester et al. 2014, 755.)

Kuopio University Hospital’s (KUH) NICU has existed in its current form since 2015. In 2015, NICU moved to new location. With new surroundings also came a new care culture. In the new unit, all patient rooms are single family rooms highlighting the importance of family integrated care. Both parents can stay in the room, where bathroom and storage space are included. The goal is that the baby is not separated from the parents at any stage of the care time in NICU. (Ojanperä & Ronkainen 2015.)

The use of digital solutions and mobile apps has increased in health care, as they offer up to date, trustworthy educative material at best. In NICU, parents have become more involved and informed of their baby’s care overall and they are eager to find more information about their baby’s wellbeing and health condition. However, the concept of mobile technology in the NICU is relatively new. Internationally there are no formal quality standards to follow when developing digital health services for NICU parents. Due to the heterogeneity of the studies available, it is often difficult to conduct further analysis of digital service’s usability. (Dol, Delahunty-Pike, Siani & Campbell-Yeo 2017, 2996.) However, there are coherent trends visible about the impact of digital services in NICU. It seems parents are willing to accept digital services as a part of their NICU journey. (Dol et al. 2017, 2996.) There are research findings suggesting that interactive features on mobile health applications together with family integrated care model may improve parental participation in the NICU. (Balasundaram et al. 2022, 110-114; Franck et al. 2019, 6-7.)

The purpose of this thesis project is to study the current state of family integrated care of premature babies in KUH NICU. The unit currently applies a paper-formed discharge plan in the family integrated care protocol. The research part of this thesis project also studies the current discharge plan’s benefits and developmental needs. It is the goal of the authors of this thesis project that the findings of this project will be further studied and developed and ultimately be developed into a completed digital care path to use in family integrated NICU.

2 DIGITAL SERVICES IN HEALTH CARE

Digitalisation of health care is an ongoing process that will influence the way health care is working now, and how it will work in the future. Digitalisation in health care had its starting point in 2005, when the World Health Assembly, WHA, stated that Member States should start planning strategies for eHealth services. Over 120 Member States have developed strategies and policies to encourage digitalisation, including in low- and middle-income countries. (Global Strategy on Digital Health 2020-2025, 4.) In 2013, the World Health Assembly adopted a resolution on eHealth standardisation and interoperability. Its objective was to encourage comprehensive national eHealth strategies including policies and legislative mechanisms. In 2018 the WHA agreed a new resolution on digital health after a consultative process. This global strategy on digital health 2020-2025 was launched in 2020. (Global Strategy on Digital Health 2020-2025, 4.) The 2030 Agenda for Sustainable Development emphasises the use of information and communications technology, and global interconnectedness has the potential to bridge the digital divide (Global Strategy on Digital Health 2020-2025, 9). The Covid-19 pandemic shook the world and started a completely new era for digitalised health services, as it increased the use of eHealth services globally. It showed the acute need for new digital health interventions. Epidemiological surveillance, contact tracing, remote appointments and eHealth services were needed, and new service models were developed. (Li Han Wong et al. 2022, 2.) The world has seen the benefits of digitalised services in health care and consequently, the developmental work is not slowing down.

2.1 The effects of digitalisation on health care

Technological transformation of health care has spread around the world. Digitally driven systems and equipment have been deployed throughout in the health care field, including management, health care delivery and administration. Diagnostics utilises digital tools and helps physicians plan the patient care optimally. Novel technology that health care utilises is for example, health cloud, mobile health (mHealth), telemedicine services, electronic medical record (EMR) systems and information technology-based assistive services. (Iyanna, Kaur, Ractham, Talwar & Islam 2022, 151.) Digital technologies enable opportunities to identify the needs and delivering health care, starting from preventing illnesses, health promotion and curative innovations to self-management. The successful digital transformation of health care is based on the deep understanding and support from the stakeholders. (European Commission 2019, 7.) The effects of digitalised health care are studied only a little. That is why European Commission has developed a framework to help the assessment of the digital transformation of health care and its effects. The results should be visible and comprehensive throughout the systems. The aim was to help EU member states with their decision-making with health policies in the future. (European Commission 2019, 10, 22.)

Rising public health care costs have forced societies to develop more efficient ways to produce services. Digitalisation of the health care supply chain should be linked to enterprise resource planning systems. Effective coordination and planning that encompasses all areas of health care systems will improve not only financial, but also patient care and safety. Digitalisation has a major effect on health care professionals work, and technology related competence is a must nowadays. The new generation of digital natives use agilely different digital services in their work. This generation has grown up using electronic devices and digital services as part of their daily lives. (Bialas, Bechtsis, Aivazidou, Achillas & Aidonis 2023, 3, 8-9.)

New health innovations like digitalisation of health services, can have both positive and negative impacts. Some citizens can take more advantage of the new services, participate in remote appointments, if they live in rural areas, or some of the citizens might find the digitalised health services to lower the service quality if they do not have for example, adequate access to high-speed internet. The decision-making bodies should always consider the overall picture to serve citizens at in the best possible way. It is challenging to evaluate the effects of digitalisation of health care as it can be diverse and have many forms. (European Commission 2019, 24-25.)

There have been several studies done to evaluate the cost-effectiveness of digital health interventions. Different kinds of digital health innovations have been implemented among different patient groups. It is shown that there is a growing need for cost-effective digital health interventions to optimise the workload of health care now and in the future. Even though implementing new technologies and training health care professionals to utilise them is not free, it will bring savings in a long run. (Gentili et al. 2022, 27-28; Jiang, Ming & You 2019.) Even though the evidence and research done to evaluate the cost-effectiveness of using digital health innovations is still limited, it can be stated that digital health interventions will lead to better efficiency in overall in health care. The outcome for patients is proven to lead to better quality of life, and the costs for society will be reduced as the human and technological resources are used in more versatile and efficient ways. (Gentil et al. 2022, 29.)

Counselling patients via a digital care path is seen as an effective way to improve care. Patients can share information considering their condition regardless the time and place. Also, health care professionals can counsel them remotely and with use of digital material, like links to guidance material. This guidance is often as effective as made by face-to-face meetings. Remote appointments are at their best when the patient lives far away from the health unit. It saves time and reduces costs when the patient can participate in the appointment at home. Also, it is possible to organise multi-professional meetings remotely where a physician, a nurse, and a patient are all present. (Kaihlaniemi, Liljamo, Rajala, Kaakinen & Oikarinen 2023, 4781.)

Patient centred care is in the focus of a modern health care. The patients' perceptions and experiences of their care are seen as an important factor leading to a comprehensive patient care. The patient's needs and values should always be heard and respected. The collaboration should flow between the patient, family, and health care professionals. One example of a modern eHealth innovation supporting patient empowerment is a digital care path. A care path is developed to meet the need of a specific patient group and it can be modified as needed. (Heijster et al. 2023.)

The importance of health care professionals' counselling competence to support patients' self-care should never be underestimated. It creates the very basis of high-quality patient care. The health care professionals must have a deep knowledge and understanding of the disease itself, but also the treatment. The knowledge about different patient groups and, how to activate and support them remotely for self-care, requires years of expertise. The interaction skills play a critical role when treating patients via digital care paths. It is not only the expertise considering the patient care itself, but the health care professional must also have competence with IT and problem-solving skills. It is possible that patients have difficulties with information technology and the health care professionals' ability to explain how to use the technology leads to better experiences for the patient. (Kaihlaniemi et al. 2023, 4777-4778.)

When patients have a feeling that the care they receive is individual, and their questions are answered, the care is seen as comprehensive. According to Kaihlaniemi et al. (2023, 4779) the patient's care is not always similar, sometimes a patient needs more motivation and support to manage with the illness she or he has. The better motivation skills the health care professional has, the better outcome for the patient. Patient empowerment is significant when the care is carried out remotely and is based on the information produced by the patient itself. (Kaihlaniemi et al. 2023, 4779.) It is important to ensure that the eHealth innovation the patient is supposed to use is understandable, accessible, and the technology used matches the needs of the specific patient. Furthermore, access to the information package must be timely to guide the patient. (Heijsters et al. 2023). The patient is not capable of receiving all the information at once. When the patient achieves the feeling of controlling their own care, their empowerment increases.

2.2 Patient involvement

Digital health improves the equity in access to health services generally. Digitalisation in health care empowers citizens to take better care of their health by accessing up-to-date information of evidence-based health policies. Empowered patients will take an active role in the decision-making process concerning their own care. The old-fashioned patriarchal hierarchy in health care is in the past. The two-way communication between the health care professional and patient is described as a partner-like relationship. A shared decision making, and active participation of the patient is empowering at its best. Due to COVID19- pandemic conditions, the importance of interminable remote access to health data was highlighted. By using digital health services, it is possible to improve the efficiency and effectiveness of public health care. (Li Han Wong et al. 2022, 2, 4-5; Meskó, Radó & Győrffy 2019, 4-5; Meskó, Drobni, Bényi, Gergely & Győrffy 2017, 2-3.)

Digital health is shaping the new roles for health care professionals and patients. The patients are seen as the centre of attention. New hardware and software enable better care for patients. Hardware technologies such as internet access and mobile phone usage have been increasing in the past decades. Software technologies include for example, the access to medical information and peer support, open access to clinical studies and guidelines. These lead to better and comprehensive health care and opportunity for self-care. (Meskó et al. 2017, 2.) Meskó et al. (2019, 5) also presented in their research that empowered patients typically found it important to have the access to health data and they are engaged in the process. It was notable that technological skills were seen as important factor to patient empowerment (Meskó et al. 2019, 5). Although there are major advantages that digitalised health services enables, it is notable that there are discrepancies in digital skills among citizens. The ones who would benefit most from the digitalised services, are often the ones who have the greatest barriers. (Li Han Wong et al. 2022, 4-5.)

Also, even though digitalisation is seen as an important change in health care, the studies show resistance to eHealth innovations. The resistance is associated with task-related patientcare and system barriers. First, task-related barriers include challenges related to communication, mainly the appropriate use of documentation systematically and miscommunication with other health care professionals. Second, patient-care barriers are related to the worry of offering best possible care to the patient. Health care professionals are reported to have concerns about eHealth innovations in patient care, especially with online interactions. It is not always possible to set a diagnosis via remote appointment. Third, system barriers refer to concerns with interface, design, quality, and reliability of the digital based system. The history has pointed out difficulties with technology reliability, for example servers crashed, and there have been difficulties with transferring patient data. (Iyanna et al. 2022, 154-155.) Digital transformation takes time and effort to implement novel innovations to patient care. The resistance will pass with time and experience. It is important that adequate training and hardware is available as the goal is to offer high quality care to patients.

2.3 Digital health strategy and services in Finland

Finland is one of the world's leading countries utilizing public e-services in health and wellbeing. Digital services are constantly being developed to serve the citizens in more versatile ways. Digitalisation in health care is seen as a complementary service to traditional health care. (Haggerty 2017, 7-8; Kyytsönen & Vehko 2022, 174-177; Lehto & Malkamäki 2023, 8.) Cost-effectiveness is a growing trend and health care is no exception. (Digitalisaatio Terveyden ja Hyvinvoinnin Tukena 2016, 4; Lehto & Malkamäki 2023, 9-10.) The common vision of digitalisation in the Ministry of Social Affairs and Health's administration by the year 2025 is customer focused. The customer is the most important, to whom the aim is to offer "Better knowledge, better choices, action and services". (Digitalisaatio Terveyden ja Hyvinvoinnin Tukena 2016, 8.)

The foundation of the Finnish government's digitisation program consists of goals expressed in its "Digitalised Public Services" and "Development of a Digital Business Growth Environment" position papers. The perspective is mainly administrative, but it encompasses all industries. (Digitalisaatio Terveyden ja Hyvinvoinnin Tukena 2016, 5.) The Program for the Promotion of Digitalisation was established by the Ministry of Finance in 2020. This program's purpose is to implement the government's stated digitisation goals. It supports public authorities' efforts to digitalise their services for citizens and businesses by the end of 2023. (Ministry of Finance 2021.) The Ministry of Social Affairs and Health has composed a strategy for enhancing electronic information management. The goal is to support reform in social and health care by providing citizens digital tools, so they can be proactive in the maintenance of their own wellbeing. Citizens are seen as information producers and consumers, and they desire to use electronic services. Information transparency is seen essential, and it must be accessible. (Ministry of Social Affairs and Health 2022; Tieto hyvinvoinnin ja uudistuvien palveluiden tukena 2014, 5, 7–8, 10.)

In Finland, Virtual hospital 2.0 was a joint project including all five Finnish university hospitals during the years 2016-2018. The primary eHealth strategy planning was instituted in the year 2014 at the Hospital District of Helsinki and Uusimaa, which was also the coordinator in the project. The project was conducted as a part of a Finnish governmental wellbeing project to develop customerresponsive services, and it has been supported by social and health ministry authorities as well as local federations. Collaboration was carried out with other national projects including “Your well-being e-services (ODA) and Isaacus – the Digital Health HUB”. During the Virtual hospital 2.0 project, digital health services were designed, produced, and implemented for citizens and patients in selected groups. These services were designed to both enhance existing face-to-face services as well as to create more comprehensive remote packages. All services designed in the Virtual hospital 2.0 project were planned so that they are compatible with other national information system services. Over 1400 professionals participated in the development of the eHealth services in the Virtual hospital 2.0 project along with the patients, and over 1700 professionals participated in the eHealth service training programs. The aim was to enhance performance, efficiency, and the value of the services to the citizens and patients, and to allow the patients’ voices and opinions to be heard. (Arvonen & Lehto-Trapnowski 2019, 3; Health Village 2020; Rauhala & Kinnunen 2017, 252-253.)

The project produced an open, public eHealth service platform named “Health Village” including self-care programs and guidance material. At present, the Health Village open website consists of over 30 virtual hubs, each of which are targeted to different patient groups. There are models available for professionals for content creation and service design, and guidelines which advise on how to work using a customer-oriented approach. The Virtual hospital 2.0 solutions are based on a national service architecture, and operators in both public and private sectors can use it. All programs in Health Village are based on the service design model and lean thinking and, the goal with these models is to advance the renewal of working policies, actions, and implementation organisations need to optimise the use of digital care solutions. (Arvonen & Lehto-Trapnowski 2019, 3; Health Village 2020; Rauhala & Kinnunen 2017, 254.)

Health Village’s digital care paths are innovative online services included in the patient’s care. The digital care path is an application using generalised service modules. With these modules, service providers can create eHealth services for different patient groups cost-effectively. The Health Village’s digital care path is referred to as “My path”, and it always includes a core digital care path and elements that are constantly evolving and updatable. Using the current paths, patients can prepare for procedures, rehabilitate postoperatively, have access to remote health services for long-term diseases and in addition, receive help in the form of remote therapy and coaching programmes. (Arvonen & Lehto-Trapnowski 2019, 3, 14–15; Health Village 2020; Liljamo, Wahlberg, Mikkonen & Reponen 2021, 163–164; Rauhala & Kinnunen 2017, 254.)

3 SERVICE DESIGN METHODOLOGY

Describing and explaining service design methodology with just one definition might not be practical, since the key to the methodology is to create new innovations and encourage fresh ways of thinking. However, Tuulaniemi (2011) presents four common attributes that can be used to describe and define the service itself. At first, the service solves a problem for the user. Second attribute reflects the process nature of the service. Third, the service can be experienced but not own it and the fourth attribute states that the communication between people is effective. In addition to the previous ones, the goal in service design always remains the same regardless, and that is customer satisfaction. (Pfannstiel, Brehmer & Rasche 2022, vi; Tuulaniemi 2011.) Service design methodology recognises a customer-oriented approach as a key factor when developing services. In service design, the purpose is to study users' thoughts about the use and operability of the designated service. The services are always planned from the human perspective. Service design provides tools to understand the developmental project comprehensively and presents approach methods. (Kueh, Peng, Ely & Durrant 2022, 116–117; Palvelumuotoilu kehittää asiakaskokemusta ja liiketoimintaa 2018; Prendiville 2019, 361; Schneider 2015.) Tuulaniemi (2011) describes in his book, that "in all its simplicity the purpose of a good service is to bring happiness to people".

3.1 Characteristics of service design

Tuulaniemi (2011) describes service design as an area of expertise to be quite young. He states that the service design we know today was born in 1990's. Then again, Polaine, Lovlie & Reason (2013, 18) say that service design goes back to at least a century, to industrial design and was inspired by designers who were determined to use for more constructive purposes the lessons gained by wartime industrialisation. It can be agreed in today's world the fundamental needs are different from those of the beginning of the 20th century and the focus all together has shifted from providing for basic daily needs and from efficient product production into maintenance, resilience, and lean consumption. Nowadays it is more about the quality of life. (Polaine et al. 2013, 18.) In the future, the importance of buying a single product or a single service might not be as meaningful as it is today, since people are more and more interested in seeking more comprehensive solutions that make their lives easier. (Tuulaniemi 2011.)

Service design is a concrete process combining the needs of the users and the expectations of the provider. Moreover, it can help organisations in detecting the strategic opportunities the existing services already have and to encourage development of something new. Service design is not a new and separate methodology, but a way to connect the traditional developmental methods with the service designing protocols. (Kueh et al. 2022, 129; Prendiville 2019, 361; Tuulaniemi 2011.) Although service design holds emotions and experiences of the users in high value, the goal is to not work with something abstract, but to bring and transform these experiences into actual service products that are economically, socially, and ecologically sustainable. (Tuulaniemi 2011.)

Because the health care industry is based on traditional assessments, it is resistant to change. Because of this, it is difficult to bring in new innovations. The innovation development requires changes in several organisational levels. This is why organisations have started to adopt service design methods in their way of working. Involving a multidisciplinary stakeholder group in the development work of service design is seen as extremely fruitful. When each member of the group is appreciated for one’s experience and knowledge, without considering hierarchies, the result can be impressive. (Prendiville 2019; 362; Vink, Joly, Wetter-Edman, Tronvoll & Edvardsson 2019, 20.) The experiences of patients and health care professionals are seen as valuable when developing something new with the help of service design.

3.2 The double diamond model

The most well-known model used in the service design process is the double diamond model (see Figure 1), first introduced by the UK Design Council (Design council 2023). It divides the process of service design into four separate stages. The first half of the design process is generally defining the correct need, problem, or a developmental issue, and the second half focuses on shaping the right solution. The double diamond model portrays and guides the process of service design clearly, regardless of what other academic methods and tools are implemented or used. It is also a way to visualise the process. The design process itself is not linear, and it is possible the underlying challenges and the feedback received during the process will also require the project to move backwards. (Design Council 2023; Palvelumuotoilun prosessin vaiheet 2018; Palvelumuotoilu kehittää asiakaskokemusta ja liiketoimintaa 2018; Schneider 2015.)

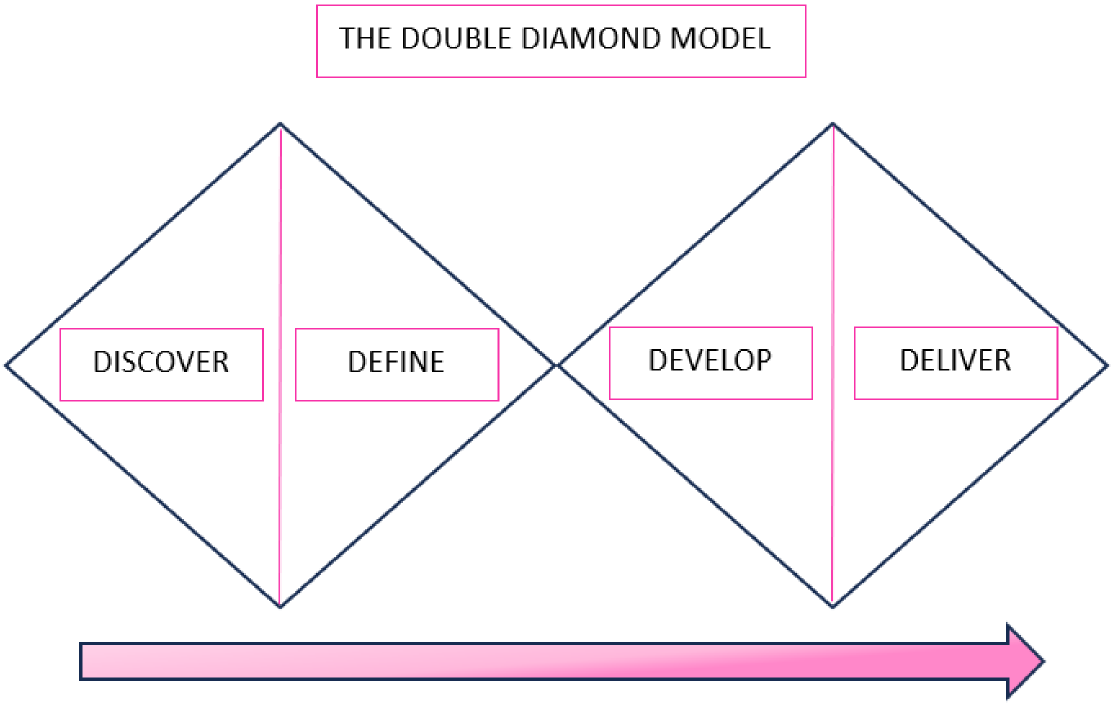


Figure 1. The double diamond model by the UK Design Council (Design Council 2023)

The Design Council encourages the double diamond model to be modified according to the individual process needs. Adding data with more detail to the original structure can result in a more realistic view of how the process truly advances. Adding more data into the original structure also makes the mistakes visible, which could be considered even advisable. A project like service designing, that does not follow one straight line, benefits from all the steps taken to be in a visual form. (Gustafsson 2019, 43.)

Discover and define

Generally, discovering and defining in the double diamond model includes recognising the developmental need or discovering a problem that initiates the need for change. It also includes defining the current state of the service entity and rationalising the target group. If an existing service is desired to be modified and developed, it is important to visualise and model the whole existing service ecosystem first to point out possible missing or useless elements. Creative thinking and dialogue with users of the existing service are essential and encouraged in the service design method from the beginning. The focus and the aims of the project need to be clear from the beginning to be able to gain a deeper understanding of the chosen developmental phenomena. The goal at this part of the process is to gather meaningful relations and recognise the complexity of the process or service that is under development. (Design Council 2023; Palvelumuotoiluprosessin vaiheet 2018; Schneider 2015; Tuulaniemi 2011.)

Service design talks about a "service experience" (palvelukokemus), when referring to the user as a part of the service in question. "Customer understanding" (asiakasymmärrys) again means, that the organisations and companies should really learn about their service users and aim to understand the circumstances and the reality surrounding them. Service experience is difficult to understand objectively since it is a subjective experience, and the user will always form this experience on a personal level when interacting with the service. Instead of planning the experience the focus should be on optimising it. Focusing on the service process entity, the surrounding space, working methods, and interactions, as well as deleting distractions in the service process can help in the optimising. (Tuulaniemi 2011.)

In addition to defining and understanding the developmental needs and user perspectives, the new service under development is frequently drafted at a very early stage even though the finalised solutions and delivering the new service design come later when using the double diamond model. (Palvelumuotoilu kehittää asiakaskokemusta ja liiketoimintaa 2018; Vilkka 2021, 23–26.) Typically, service design process is a back-and-forth process where you can go back to a previous stage and rethink its implementation. The process is not linear, and some steps are connected as the process continues. (De Goey, Hilletofth & Eriksson 2019, 724.) Services and service designing are complex systems. Bringing everyone – including service users and operators in all organisational levels - together for this early drafting is the goal in service design, since it engages the parties in collaborative work at an early stage. (Palvelumuotoiluprosessin vaiheet 2018; Tuulaniemi 2011.)

The discovering phase of the project is characterised by tools like brainstorming, fast visualisation, observing, surveys, and simply creating the space for the project. The idea is to find what best suits the project at hand and to get started with the recognised idea or the problem to be solved. The goal is to gain information on the chosen topic, to identify the users of the service and let the mind flow with ideas. The work will continue in the defining phase with tools like customer journey mapping. This is a representation of a user's journey through a service, portraying the interactions and service experiences they have had. Assessing the ideas is also important in the defining phase. Only the promising ideas should be selected to be developed further. (Design Council 2023.)

It has been suggested and recognised that even the first part of the diamond should be in some cases split further into two separate efforts. This could help with identifying the resources better to known themes. As mentioned earlier, it is more rational to recognise first the most important challenges in a service as well as the internal goals. (Palvelumuotoiluprosessin vaiheet 2018.)

Develop and deliver

The developmental phase aims to explore solutions to the challenge by using creative design and human-driven methods. The chosen method is finalised and executed for launching in the delivery phase. (Palvelumuotoilun prosessin vaiheet 2018; Schneider 2015.)

During development, the visualisations and ideas are transformed into concrete concepts that can be actualised into a service. Prototypes, testing, demos, and demonstrations are commonly used. For example, a service blueprint can be created to visualise the total service in detail, portraying the complete journey of the user. It differs from journey mapping since a blueprint also includes the parts of the service not necessarily visible to the user, but that are mandatory touchpoints and channels for the service to work. During development the designers can build physical prototypes that can be easily tested with a small group of target users. The prototype model can be then modified into a more accurate and descriptive one with perfected details and functions when advancing to later stages in the process. Physical prototypes are good for recognising faults and give an idea of how the finalised design may be used. In the delivery phase final testing, evaluation, risk management and getting feedback finalise the process before releasing the complete service designed. (Design Council 2023; Palvelumuotoiluprosessin vaiheet 2018.)

4 NEONATAL INTENSIVE CARE UNIT AND FAMILY INTEGRATED CARE

The history of neonatology is not that long. Prematurely born babies were routinely sent home up until the 1950's without receiving any specialised care. Most of them did not survive past their first birthday. In the 1960's the terms of neonatology and specialised care of premature babies were introduced. (NICU Awareness 2016; Philip 2005, 799-800.) In the 1980's new treatments were deployed and afterwards, many of these were discarded as useless or even dangerous. From the late 1980's multi-centred research has been seen as an important clinical research method in neonatal intensive care. International databases, like The Vermont-Oxford Network, that aims to analyse and provide data about neonatal care has spread around the world. The goal is to improve the quality of care of prematurely born babies by benchmarking. (Lehtonen 2009, 1333.)

In Finland, a paediatrician named Arvo Ylppö has played a key role of developing the care of preterm babies (Philip 2005, 800). The first national research, led by Ylppö, concerning preterm babies started in the 1950's. It monitored prematurely born babies physiological and emotional development until they were school age. This comprehensive research showed that preterm babies treated well did get a good start to their lives. This development work in Finland took quite a long time. The nursing of prematurely born babies provided by the private sector was not finished until the 1960's, when the system of central hospitals and their paediatric units were introduced. (Raivio s.a.)

Beyond the significant development of medical treatment of premature babies from the 1950's, also the significance of parental participation is recognised differently nowadays in the NICU era. It is not that long ago, when families had only restricted visiting hours and very limited possibilities to nurse their baby while staying in the NICU's. However, nowadays it is known how beneficial it is to enable continuous presence of parents with their premature baby. A family integrated approach and single-family rooms are seen as the standard for modern neonatology. Family integrated care is the most efficient way to support parental bonding since the key element in this approach is to not separate families from their newborn baby in need of intensive care.

4.1 Characteristics of premature babies' care in NICU

Research suggests multiple ways to sub-categorise preterm babies, and the categorisation many times is based on the level of anatomical and physiological immaturity (Keskosuuden määritelmä 2019; Meeks et al. 2010, 71; WHO 2018.) The World Health Organization, WHO, has further defined preterm babies by sub-categories according to the weeks of gestational age when they were born. WHO uses the term very preterm when the baby is born between 28 to 32 weeks of gestational age, and an extremely preterm baby is a baby born before 28 weeks of gestational age. Babies born before 34 weeks of gestational age are called moderately preterm babies. (WHO 2018.) In addition to the gestational age, the level of prematurity can also be defined according to the birth weight. A very preterm baby is born before 32 weeks of gestational age and/or weights under 1500g. (Keskosuuden määritelmä 2019.) International Classification of Diseases also uses the birthweight as a classification method. This is a good way to define prematurity since there is evidence about birth weight of a baby following the duration of pregnancy. (Meeks et al. 2010, 66, 71.)

Despite the development of care the hospitalisation period of prematurely born babies is still long because of the overall immatureness. (Lehtonen 2009, 1336–1337.) Typical care times for preterm babies vary from one month to four months. (Banerjee et al. 2017, 8). Similar hospitalisation duration was found in a study performed by Maier et al. (2018, 1155). A very preterm baby's, defined as 26 or less weeks of gestational age, median length of hospitalisation is around 92 days. This being around 2,5 months, meaning around one week before their full-term due date. On the other hand, when a 31 weeks of gestational age baby is born, the median length of stay is around 34 days. (Korja & Latva 2017, 235; Seaton et al. 2019, 184.)

The NICU path of a preterm baby is always challenging and unique. The care of a preterm differs significantly from those who are full term. The severity of the challenges correlates at least to some extent with the gestational age at birth. Also, the reason for premature birth influences the difficulty level of the care. Prematurely born babies are prone to complications and have a higher risk for severe morbidities. These morbidities may include respiratory and cardiovascular issues as well as infections, neurological issues, and immature metabolic function. The body of a preterm baby is extremely fragile overall. The more preterm the baby, the greater the expected need for longer respiratory support, intravenous nutrition, constant monitoring, and several medications. They are exposed to a lot of stress and depending on their condition, may need to undergo multiple procedures during their stay at the NICU. (Collins, Weitkamp & Wynn 2018, 391; Helenius 2020, 14-18; Meeks et al. 2010, 71-72.)

4.2 Family integrated care model ensures parental participation and growth

The environment of a modern neonatal intensive care unit itself is technical and parents usually have found it scary. Preterm babies are separated from their parents physically and mentally, which is nowadays known to be harmful. To change that dilemma, there are several procedures made to build the relationship between the preterm baby and the parents. Kangaroo care, skin-to-skin care, and family centred care are seen to strengthen parental commitment to their infant. Earlier the common understanding supported the idea that only NICU professionals are allowed to care for premature babies and parents are only visitors at the unit. The research done earlier noticed that parents are willing and able to take care of their preterm babies in the NICU, and it would benefit the whole family. Although the advantages were seen, there was no clear protocol to follow. That is why researchers implemented the Family Integrated Care model in a pilot study. The pilot's multidisciplinary team consisted of parents of prior NICU babies; so-called "veteran parents", a parent educator, NICU nurses, a physician, a lactation consultant, and a social worker. (O'Brien et al. 2013, 2.)

The FICare's collaborative model by O'Brien et al. (2013, 3, 6) includes four different sectors to involve parents in the neonatal care team and minimise the separation. These sectors encompass educational, psychological, communication, and environmental issues. The key to the whole program was to support adequate education for both NICU nurses and the parents of the preterm baby. It was done by two specially developed curricula that supported them to adapt to their new roles in the care of a preterm baby. Psychological and physical support were also provided. The veteran parents had previous experience of NICU life with their own baby and they were able to offer peer support for parents. The support was performed face-to-face as one of them was present at the unit for a half-day a week. The veteran parents guided or co-guided the FICare education sessions for parents. Also, other activities like coffee hour were available. Physical support consisted of things like parking passes, a room for resting, kitchen area, and breast pumps available at bedsides. Low threshold access to social workers was available and seen as an important service for parents. When any problems with communication arose, the help was easy to get. (O'Brien et al. 2013, 2-3; Waddington, van Veenendaal, O'Brien & Patel 2021, 149.)

The pilot study made by O'Brien et al. (2013, 4) revealed a notable weight gain and decreased incidents of stage 3 or higher retinopathy of prematurity (National Eye Institute 2022), among the FICare group, compared to the control group. Also, the rate of breastfeeding at discharge was significantly higher compared to the control group. Maternal stress levels at the time of discharge were reported to decrease. The overall confidence to go home with the premature baby was greater compared to the control group. (O'Brien et al. 2013, 4-6.) It is notable how comprehensive short- and long-term benefits the family integrated care offers. The benefits concern preterm babies, their families, and health care professionals.

4.2.1 Meaning of supportive environment

When a baby is born prematurely, a part of parental identity is shattered. Pregnancy is not just for raising the baby, but it is time for parents to prepare themselves for a new chapter in their lives. Usually, a premature birth comes unplanned and suddenly, leaving the parents unprepared and fearing for their baby's survival. The intensive care needs of a premature baby create a physical barrier between the newly formed family. Extremely premature babies spend their first weeks inside an incubator, attached to monitors and covered in medical equipment necessary for their survival. With extremely preterm babies their skin is even too immature to touch at first. In addition, there is psychological and emotional separation. Premature birth is traumatising at its worst, and even when premature babies are mature enough to transfer from incubator to a normal crib, there are still monitoring wires, like EKG and pulse oximeter attached. Premature babies typically need breathing support like nasal high flow therapy and nasogastric tube for feeding assistance up to very close to their discharge. (Korja & Latva 2017, 234-235.) Luckily, recent studies together with practical care have shown that parental involvement is possible even with extremely preterm babies.

Common understanding agrees that the parents of a baby are the main source of the baby's strength and support, and psychological well-being of parents is known to influence the forming of a parent-infant relationship. However, premature birth may negatively impact parents' expectations and vision of the newborn baby they have pictured during pregnancy. Parents may blame themselves for the situation, feeling guilt and anger. Parental bonding in the NICU takes a lot of time and effort because the parents might feel the small fragile premature is not their child, but rather the hospital's. (Banerjee et al. 2017, 8-9; Gehl, Alter, Gunther & Russell 2019, 59, 66-67; Pettoello-Mantovani, Campanozzi, Maiuri & Giardino 2009.)

Research shows how vital the physical and emotional parent-infant closeness is for the preterm baby. The neurobiological development lies in the very early stages of life. To support this, a new protocol for very early preterm babies has been studied. The idea is to place them into mother's skin-to-skin care after delivery when it is determined to be safe, and if certain criteria are met. The mother together with the premature baby will stay in skin-to-skin contact in delivery room for two hours monitored before transferred together to NICU. The precluding criteria for babies whose birth weight is lower that 1000g, include the need for oxygen over 40% at 20 minutes of age, or intubation, or severe congenital malformations. The maternal preclude criteria was only a general anaesthesia. Right after initial stabilisation, the preterm baby was placed on the mother's bare chest. The research showed that mothers that had the possibility to hold their preterm baby in skin-to-skin contact were satisfied. The affirmation of the newborn's living, the fact they could feel the baby's breathing, was described as significant. The continuous presence of health care professionals in the delivery room was appreciated, and it created the feeling of safety. The mothers pointed out that they were always updated during the skin-to-skin contact, even though there were medical emergency equipment involved in the situation. The preterm birth is always a stressful and scary situation for the family, causing anxiety, and the early skin-to-skin contact, and prevention of separation has been shown to be crucial for developing the parenthood. (Føreland, Engesland, Kristofferson & Fegran 2022, 2-6.) It has strong evidence based on the baby's ability to form social contacts, and it supports physical, emotional, and mental wellbeing overall. The parents of the preterm baby stimulate the behavioural and neurobiological processes and helps the infant's response to pain and stress. It is shown that separation between parents and infants will prevent the crucial biophysiological and emotional processes, the development of parenthood, parent-infant relationship, and attachment. (Waddington et al. 2021, 149-150.)

4.2.2 Educating parents through the hospitalisation time

In a family integrated care approach NICU staff encourage parents to act as primary caregivers to their babies in NICU daily. The aim is to minimise the negative aspects of the NICU environment. Family integrated care highlights the need for the families to be at the centre of neonatal care delivery from the very beginning, even during the first critical days or weeks. This care model includes the belief that parents of the preterm baby and NICU staff should act as a collaborative care team for the baby. NICU staff will promote sufficient education and support for the parents to feel confident as independent caregivers of their baby. The parents will become integrated as equal partners in the neonatal team. (Lehtonen 2009, 1336–1337; Waddington et al. 2021, 149-152.)

Even though the experiences of parents of preterm birth have been studied for decades, only a little is known about the knowledge and skills of parents while they stay in the NICU. More research is needed to gain better understanding of the needs of parental education. Furtak et al. (2021, 2733) have studied the information necessities of parents' and what kind of worries they have while being hospitalised at NICU. The questions and concerns have to do with the baby's prognosis, feeding issues, experiencing pain, but also about when or how they can they touch their baby and participate somehow in the care of their baby. The studies have shown that even though there might be a specific parental education program to follow, guiding is dependent on the nurse who is on shift. There is not usually a formal curriculum to follow. (Furtak et al. 2021, 2734-2737.) The systematic review about the effectiveness of parental education programs made by Springer, Cooper

& Elleman (2023, 5-7) revealed that there are different kinds of methods implemented and used to educate NICU parents. According to the review, those interventions include methods such as written and face-to-face given guidance, technology-based, simulations and mixed of the above. The most used method was reported to be face-to-face given guidance. The review stated that all educative guidance for NICU parents improves parental confidence and prepares them for the discharge. (Springer et al. 2023, 3, 5-6.) These studies altogether support the idea of an appropriate parental education program is needed.

The study revealed parents' will to learn more about their baby's medical condition. For example, a respiratory related diagnosis was set with half of the study group of patients. Also, medication and feeding issues, as well as parenting care was named as the themes parents request to learn more about. It was noted that there was a difference between the learning needs depending on the phase of the hospitalisation. In the first third of hospitalisation, parents reported the need to gain information about the baby's prognosis, diagnosis, respiratory interventions such as ventilation support, and parenting skills such as diaper changing and observing the baby's signals. As the hospitalisation continued, the questions related to baby's medical course remained, and learning needs for feeding the baby arose. The parents were reported to have questions about breastfeeding and bottle-feeding with a preterm baby. Also, as adaptation to the situation proceeded, parents requested to learn more about their baby's clinical condition and to learn specialised care related to the baby's condition as a premature baby. The baby might have a respiratory intervention to support baby's breathing and/or nasogastric tube to help feeding. At the final third of hospitalisation, parents reported to have questions related to topics mentioned above, and as the time of discharge was getting closer, they expressed a need for gaining knowledge of interpreting the baby's symptoms and cues for communication. Also, as prematurely born babies typically need medication after discharge, parents expressed their need to fully understand and manage the medical care in a home environment. (Furtak et al. 2021, 2733-2734.)

The timeline of guiding the parents of a premature baby is relatively short. There is a lot of information to share, and it is individual due to how different people can process information in a particularly stressful time. High stress levels are known to affect to ability to learn something new. The ability to concentrate might be weakened. Parental education programmes have been developed to share the information needed before the baby is ready to be discharged. The goal is to ease parental stress, support them to participate in the care of their preterm baby from the beginning of the hospitalisation, and prepare the family for discharge. Different educational methods are used to support the learning, such as videos, group educational sessions, and bedside simulations. In the NICU environment, the guiding sessions might be challenging to carry out as the situation might change rapidly at the unit. (Gehl et al. 2019, 59-60.) The education parents valued the most concerned baby's feeding; both breastfeeding and bottle feeding was named. Also, CPR and parenting skills were seen as the most valuable things they have learned during hospitalisation. (Furtak et al. 2021, 2734-2735.) It is understandable that parents of a premature baby need to know things that matter in their daily lives. They want to gain knowledge, how to take care for their baby who has special needs, and to manage with the health issues prematurity might cause for the baby.

4.2.3 Peer and professional support systems

Parents of preterm babies seek peer-support and information from social media platforms. Interventions made at the family centred NICU, and offering support groups for parents are seen as low threshold services. The support group can be led by a parent of a premature baby or by a NICU nurse. Studies have shown benefits of participating in support groups, especially led by a peer-parent. Peer support is shown to benefit parents emotionally, informationally, and it will give them more strength to cope with shared challenges. The stress levels decreased notably with mothers if they participated in a support group. Also, maternal-infant relationship and home environment were better compared to the control group. Qualitative studies show how parents of premature babies benefit from sessions led by a health care professional. The parents feel more confident and gain practical information about how to communicate with their baby. Also, support groups led by a professional, were shown to ease anxiety experienced by parents. The parents had an opportunity to communicate with health care professionals and share their feelings. (Brett, Staniszewska, Newburn, Jones & Taylor 2011, 3-7.)

In one study, most of the parents expressed an interest in joining a Facebook group that provided general information about prematurity, explanation of medical terms commonly used in NICU, and detailed information about common medical problems and their care. Parents also hoped for information about follow-up services. (Lakshnanan et al. 2019, 10-11.) Social media has its pros and cons when it comes to finding information. The trustworthiness depends on the source used, and if the user does not have digital literacy skills, there is a risk for misunderstanding the false information. On the other hand, the access to information is always available, and if trustworthy sites are used, the information is updated and correct. (Sun, Zhang, Gwizdka & Trace 2019.)

4.2.4 Well educated health care professionals

The family integrated care implementation demands commitment from NICU staff. The implementation process requires a change of attitudes and behaviour to communicate better with the parents. The nursing staff have expanded roles as mentors, supporters, and educators. A supportive environment and good communication are crucial for the parents to have the courage to assume roles as primary caregivers. Multi-disciplinary commitment, sufficient resources, and time for preparation, and most of all staff motivation are crucial factors leading to success in family integrated care. Building the partnership with parents is not simple, but a shared vision of supporting parent-infant closeness and involving parents in the care of their preterm baby is essential. Over time, parents can become experts in providing care for their baby during NICU time. (Waddington et al. 2021, 150–151.)

Premature babies require specialised care right after they have been born. The health care professionals' education must be up-to-date, and they must have experience of working with neonates. As the rate of morbidity is higher among preterm babies compared to full term babies, continuous training and education is crucial. NICU nurses must be capable of working under stressful, ever changeable medical emergency incidents. The importance of maintaining calm has proven to also help the parents of the preterm baby as they see the professionals will do their best even in critical situations. The needs of preterm babies concern general and specialised medicines along with surgical needs. The degree program in nursing offers only general nursing skills. The specialised units will provide the needed education and training for its employees. Especially in the intensive care unit, the simulation practice is proven to be crucial to help working in acute medical emergency situations. (Rahimi et al. 2018.)

In the NICU, the ability to work together as a team to promote the health of sick premature baby, is a necessary skill. This is why good communication skills is a must, as you must be able to communicate clearly and use good manners. Teamwork is seen as a normal procedure in resuscitation incidents and invasive procedures such as intubation and administration of surfactant therapy for the baby. Continuous education and education provided by a more experienced nurse is common practice nowadays. An experimental study was performed by Rahimi et al. (2018) to assess the impact of training on nurses' knowledge and nursing skills working at NICU. The study showed that the learning process depends on the person's personal ability to process the information and transfer it to the daily working life. The education gets deeper into the medical challenges and severe patient cases as the experience is built with NICU patients. Interactive education sessions were performed through presentations about neonatal medicine, infectious disease control, surgery, and other treatments specific to care of newborns. The nurses learned as they gained a deeper understanding of neonatal care, how and why certain procedures were made. For example, they learned how to position a preterm baby with intubation tube and invasive lines safely. The learning was evaluated by using tests on different phases of the study, and quizzes about different sections of the education content. There was noted significant differences between results of mid and final quizzes. The research showed substantial and positive impact from continuous training of nurses. The education seemed to motivate NICU nurses to perform high quality care for preterm babies and their families. (Rahimi et al. 2018.) NICU nurses are very motivated by continuous learning as it helps them in their daily working life at NICU.

4.3 Discharge planning and programs in NICU

Discharge planning and programming can help a NICU family to transition home successfully with all their needs met. Creating a comprehensive plan suitable for all families in all situations is impossible. The structure of a discharge plan needs to be adaptable, since for the best results it needs to be made based on the family and their baby's individual needs. (Smith, Love & Goyer 2022, 7.) Research shows that inadequate discharge planning increases risk for readmissions, emergency department visits, anxiety experienced by parents of the premature baby, and difficulties with feeding. The quality of the discharge planning is seen as a significant predicator of readiness to be discharged. (Balasundaram et al. 2022, 116-117.)

Smith et al. (2022, 7) put together guidelines for NICU discharge focusing on content and process. The foundation of these guidelines came from existing literature, policies, and statements by professionals. They divided their guidelines into five sections, covering the following topics: basic information, anticipatory guidance, family and home needs assessment, transfer and coordination of care and other important considerations. The researchers state it is important the family participates into the discharge planning, and that the NICU team communicates with the family about the care path in NICU comprehensively. Consistency in given information as well as emphasising the amount of uncertainty when it comes to planning an exact discharge time is also seen as crucial. Studies suggests that clear criteria need to be set for discharge readiness, and to minimise disappointment and frustration. It is important the families understand it is still often depending on the circumstances. (Smith et al. 2022, 7.) It is also important to point out that even if it is a risk to predict the discharge time for the parents as there is no guarantee, parents have reported that an estimated length of stay will help them to prepare for their time in hospital (Seaton et al. 2019).

The recommendation concerning the educational content parents should receive by the time of discharge was set to guarantee that families have adequate information and skills to provide the care needed by the preterm baby at home. The topic covers for example, demonstration of skills for baby's care, the assessment of family's overall understanding of the situation, and planning the optimal timing of the discharge education. The education process should fulfil all the needs that parents must have to deal with their baby at home. The educational content covers issues from basic nursing skills, understanding the baby's cues and signals of medical concerns, when to reach for medical help, infection prevention, and follow-up schedules. Discharge planning tools were developed to help the health care professionals work to support families' discharge preparations. (Smith et al. 2022, 8-10.)

The tools presented in the recommendation include discharge summary, NICU hospital roadmap, and a discharge planning folder. The discharge summary includes medical information concerning the premature baby, such as diagnosis, medications at discharge and its administration instructions, home feeding plan, hearing screen result, car seat screening result, immunisations administered and the plan to administer them in the future, contact information after the discharge, and a schedule for follow-ups. The NICU roadmap is a visual chart to demonstrate the timeline at NICU. It has a starting point from the baby's birth and admission at NICU up until the discharge. The road map shows educational goals during the hospitalisation and a suggested timeline to master them. There is also shown typical milestones for the preterm baby to achieve, but it is notable that there is always an individual development progression with ups and downs. The follow-up needs for short- and long-term are presented on the map and a possible transition plan to paediatric care. The discharge planning folder shows the discharge planning process, including checklist and other educational material for the family and staff. By using a check list, it is easy to follow and keep track the discharge preparation process. (Balasundaram et al. 2022, 113-114; Smith et al. 2022, 8-11.)

It is not only one NICU nurse who oversees the discharge planning. There is usually a team of health care professionals working together. The recommendation suggests a multi-professional team to be utilised in the discharge planning. The team could consist of a physician, NICU nurses, social workers, psychologists, and possible discharge planners. Every one of them have their own responsibilities to take care of and communicate with other professionals within the team to offer the family a comprehensive service. The members of the nursing team who has worked most with the family knows best how and when the family is ready to go home. Also, they have gained knowledge about parents' unique strengths and challenges. (Smith et al. 2022, 9-10.) Communication between the family and health care professional is a must during the discharge process. Every family's ability to care for their baby is different due to different medical conditions and the family’s coping skills. Some families need more time and repetition to be able to take responsibility of issues that are basic for some other families. All families should be respected, and extra attention given to support them when they need it. (Balasundaram 2022, 9; Smith et al. 2022, 8-11.)

Technology has been used in health care for years by now. Technology based applications have been adopted to the discharge process recently, and the studies show them to be effective. Inpatient applications have been used in adult settings successfully for patient education. Balasundaram et al. (2022, 110) developed an electronic book for discharge education. The aim was to change all education material into digital format for parents to improve the discharge process. The e-book was uploaded to tablets at local NICU or it was accessible on parents’ own mobile devices to review at their own pace. After the parents had completed the material, they could mark the section as done. The information flows straight to the system. If something was uncertain or they did not understand, they could mark it, and the NICU nurse was able to explain the issue for the parents. The research group also developed a checklist to observe the discharge education process. At first, the checklist was in a paper format, but later it was redesigned into a digital format and brought in the EHR. The e-book and the checklist were both modified after receiving feedback from the end-users. The discharge education and checklist were both activated at the time of admission, and the tablet was kept inside each patient room for the hospitalisation period. (Balasundaram et al. 2022, 110-114.)

After discharge, a protocol for follow-up calls to the family was deployed. The families initially expressed feelings of being disconnected after leaving NICU. The new protocol included two calls made between weeks one to four after discharge from NICU. The results showed improved satisfaction among families after such development work with the discharge process. The parents expressed the transition to home was eased as discharge was processed incrementally during the entire hospitalisation period compared to all the information flow at the day of discharge. Although the electronic education material was comprehensive, it did not replace the bedside education and communication between the parents and health care professional. (Balasundaram 2022, 114, 116.)

In one study, parents pointed out that sometimes they tend to forget the paper forms concerning discharge and suggested it would be beneficial to have the information in a digital form, so they could “just look at it”. There is also somewhat consistent data about the reduced length of NICU stay related to the parents using eHealth solutions during NICU hospitalisation time. Dol et al. (2017, 2996) found in their systematic review that there was a trend towards reduced length of stay among those babies whose parents accessed the eHealth solutions available. This study included also very preterm babies. (Dol et al. 2017, 2996.) Offering NICU families the time and support they need at the time will build the confidence and trust to manage life with a premature baby.

5 PURPOSE, GOAL AND THESIS RESEARCH QUESTIONS

The purpose of this thesis project was to study the current state of family integrated care of premature babies in Kuopio University Hospital (KUH) NICU.

The goal was that findings of this thesis can be used for future development of a digital care path in KUH NICU.

Two research tasks were defined. KUH NICU currently uses a printed discharge plan in the family integrated care protocol. The research tasks were the following:

1. Study the current state of family integrated care at KUH NICU.
2. Study how the current discharge plan is working.

6 RESEARCH METHODOLOGIES

The idea for this thesis originated when developmental projects were discussed with the department managers and head physician of KUH NICU in 2021. The idea of developing a digital care path was introduced. A digital care path was seen as a solution to not only standardise given guidance, but also help bring the current KUH NICU discharge plan into more regular use and moreover, help further develop family integrated care. A digital care path that is meant to be used during a long hospitalisation time is a new perspective in Finland. The idea was to start developing a digital care path precisely for preterm born babies and their parents. Since KUH NICU also provides care for sick full-term babies and all under 1-year-old children in need of intensive care or monitoring, it was seen as an important outlining factor to limit the target group to babies born prematurely in KUH NICU before gestational age of 34 week based on the characteristics of the current care path in general. It was important to plan the participation of the parents in determining the current state of family integrated care in KUH NICU, as well as to study the developmental needs of the current discharge plan. Qualitative research method was chosen naturally for this thesis. Implementing service design methodology required a customer-oriented approach in this thesis, and thematic interviews were seen as the most proper way to collect experience-based data on the current state of KUH NICU family integrated care protocols.

6.1 Implementation of service design

The original thesis plan was to follow the steps of the double diamond model and end up with pilot ready demo version of a digital care path for premature babies in KUH NICU, following the original developmental idea discussed before the thesis project started. In this plan the discovering phase of the model was originally initiated before the actual thesis project and research started. Drafting the thesis process and the research plan with the double diamond model gave visualisation and better understanding of the upcoming phases and tasks related (Design Council 2023; Hirsjärvi & Hurme 2022; 55.)

The discovered need led to the latter plan of starting a developmental project for a digital care path design. The goal of the defining phase was to explore, what the current care protocols in KUH NICU have to offer and find out if there are protocols in place that as they exist give an opportunity to be implemented in the design process of a digital care path. In other words, the defining phase was about studying the current state of family integrated care protocols in KUH NICU. The goal was not to completely develop something new from scratch, but to find the beneficial things from current policies as well as the developmental needs to plan a new service. (Design Council 2023; Kueh et al. 2022, 129; Prendiville 2019, 361; Tuulaniemi 2011.) To define the current state of family integrated care protocols in a collaborative and user-centred way the goal was to interview the parents (user of the current service) of premature babies born at KUH NICU before gestational age of 34 weeks using thematical interviews. (Palvelumuotoiluprosessin vaiheet 2018; Tuulaniemi 2011.) The goal was to gather subjective, meaningful experiences of parents who spent their care path in KUH NICU, and to give them space to express their feelings and thoughts, along with the possible criticism. Ultimately the hope was parents would speak up also about the developmental needs of the current care path protocols freely and comprehensively, not just about certain part or issue. It was important to collect data of the whole process, including the NICU environment, interactions and of possible distractions to create a comprehensive picture of what is currently provided to the families in KUH NICU. (Tuulaniemi 2011.)

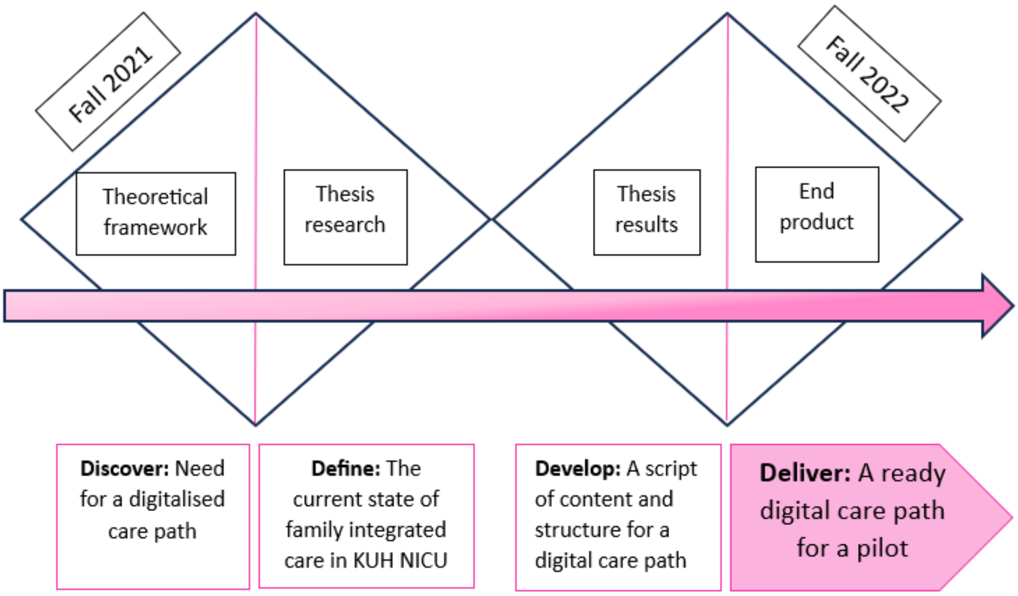


Figure 2. The original thesis idea and process portrayed with the UK Design Council’s double diamond model (Design Council 2023)

As a comparison, Figures 2 and 3 present the process of this thesis. Figure 2 above presents the original idea where the goal was to create a demo version of the digital care path. After defining phase, the goal was to have enough data of the interviews to create a script and structure of the content for the digital care path. The interviews would be formed into a customer journey map, and in developmental phase the script of the digital care path would also be a service blueprint. Ultimately, the script was meant to be transferred into a digital care path base in Health Village as a demo, for a pilot testing. (Design Council 2023; Palvelumuotoiluprosessin vaiheet 2018.) As the theoretical framework was progressing and the thesis research was planned, it soon became clear that the original plan needed to be condensed. The delays in obtaining a research permit and challenges in recruiting parents for the thematical interviews were influential to the original goal set for the thesis process. The most rational decision was to focus on the discovering and defining phases of the double diamond model (see Figure 3), making the goal of this thesis to define the current state of the service (Design Council 2023; Palvelumuotoiluprosessin vaiheet 2018).

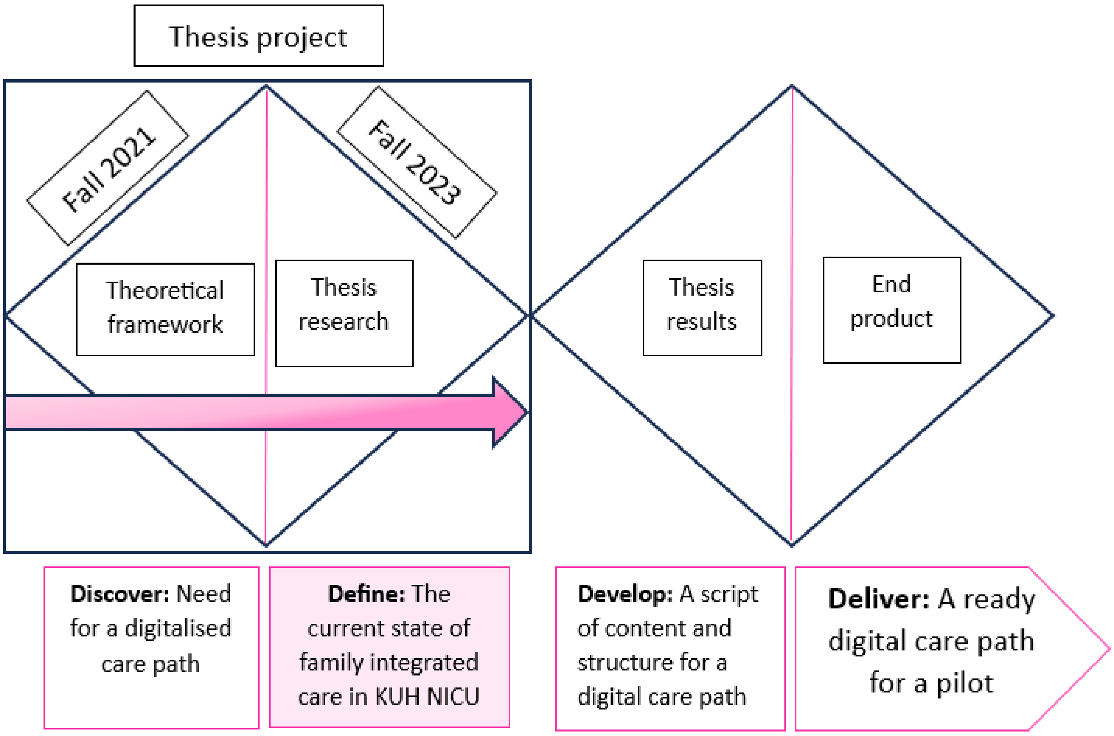


Figure 3. The completed thesis project goal and schedule (Design Council 2023)

6.2 The thesis research process

A research permit was applied for and granted to have permission to interview the parents (see Appendix 1) for the time of 6.6.-31.12.2022. Because of a critical delay in the handling process, the actual research permit was deployed 8th of September 2022 (see Appendix 1), giving three months less time to actualise the research plan, contrary to the granting date visible on the permit. The 6.6.2022 was the date when the original research permit application was sent, and it was granted retroactively. Figure 4 presents the thesis research plan process with the actualised schedule.

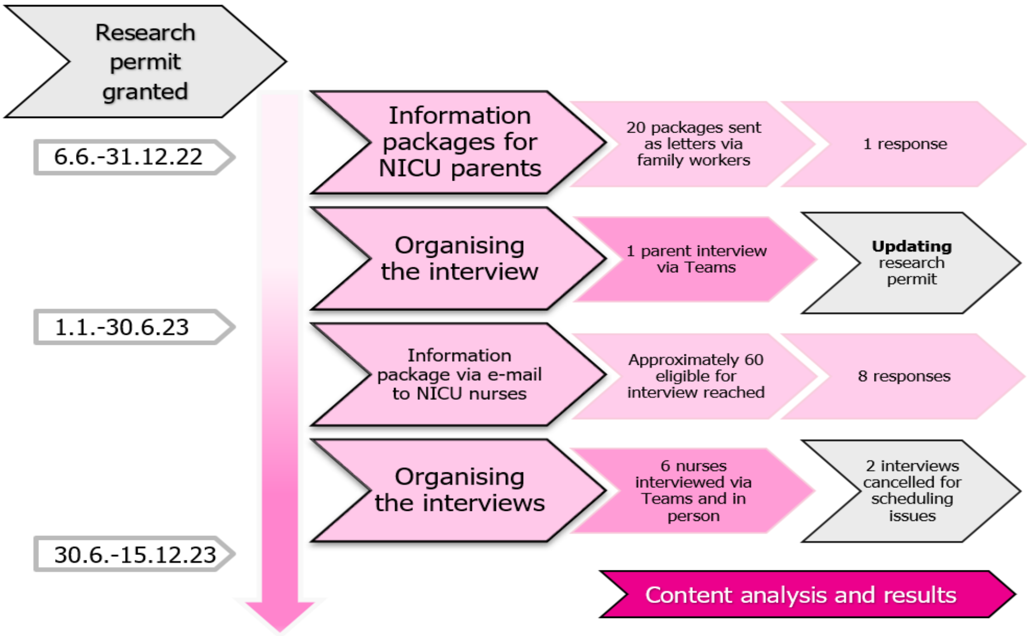


Figure 4. The thesis research plan process flow chart

When planning the recruiting of the interviewees, the only crucial thing the researcher needs to know is the eligibility of the chosen people. Knowing the names or other personal data is not necessary at this point if the recruiting is done with the help of a community, a registry or a person representing or in touch with the target group. (Hirsjärvi & Hurme 2022, 85.) Finding the families that had been already discharged from KUH NICU and meeting the target group criteria was done with the help of KUH NICU family workers, who remain in contact with the families after discharge through home visits and neonatal polyclinic. At NICU, the shift manager and the unit managers acted as information sources. This plan made it possible to not have to handle any personal data before an actual agreement to participate in the study was received from either of the parents.

A total of 20 letters were sent out to recruit parents for the interviews through the family workers during the research permit time. Those letters covered all eligible families that still had a care contact with NICU in some form. The letters contained a cover letter, privacy statement, consent forms and thematic interview themes (see Appendices 2-4). Both parents from one family were eligible to participate in the research, either being interviewed together or separately. The families eligible for the interviews were the ones that had an existing care contact to KUH NICU at the time the interviews were organised. The goal was to recruit parents who were close to discharge or had already been discharged from KUH NICU. Excluding criteria also include families discharged from KUH NICU to a local central hospital and discharged home from there. The purpose was to collect data from the families who have spent their whole care path at KUH NICU. The maximum number of participants was not limited, and the goal was to contact all eligible families.

The recruiting resulted in only one volunteer family willing to participate in the interview, and the initial consent contained the willingness of both parents to participate, however due to scheduling difficulties only one parent was interviewed. Recruiting only one family during the research permit time resulted in changing the thesis research plan.

It was decided registered nurses from KUH NICU will be recruited for the thematic interviews, applying the same interview protocol, and targeting the same research goal as with the family to gain more data (see Appendix 1). When the necessary changes were made to the original research permit application, it was sent for handling. A delay occurred again in the handling, delaying the research process with a month.

It was deemed important to classify the nurse participants by work experience. Nurses that could be included should have at least two years of working experience in KUH NICU. The two-year timeline was set since it essentially guaranteed the nurses participating had worked with families that were in KUH NICU with a premature baby born under 34 weeks of gestational age. The idea was to go through the same interview body, but from the nursing perspective of family integrated care in KUH NICU. The staff of NICU was contacted through an email sent to all nurses. The idea was that the nurses who wanted to participate would reach out to the thesis workers voluntarily, when first familiarising themselves with the inclusion criteria provided in the e-mail. Eight nurses responded and were willing to participate. Six interviews were completed during the research permit time, and two interviews were cancelled because of scheduling difficulties.

6.2.1 Qualitative research and thematic interviews

Qualitative research aims to examine the subjective experiences or views of the people under investigation. The analysis and results provided by a qualitative research aim to create a well-founded, holistic interpretation of the chosen phenomena. When reporting the results, the aim is to compile a clear and comprehensive description of the overall process and its stages. Qualitative research has been influenced by many different disciplines, which is why it is used in different ways. The content analysis can be done either using theory-related, theory-oriented, or material-oriented approach. (Puusa 2020, 141-142, 146.)

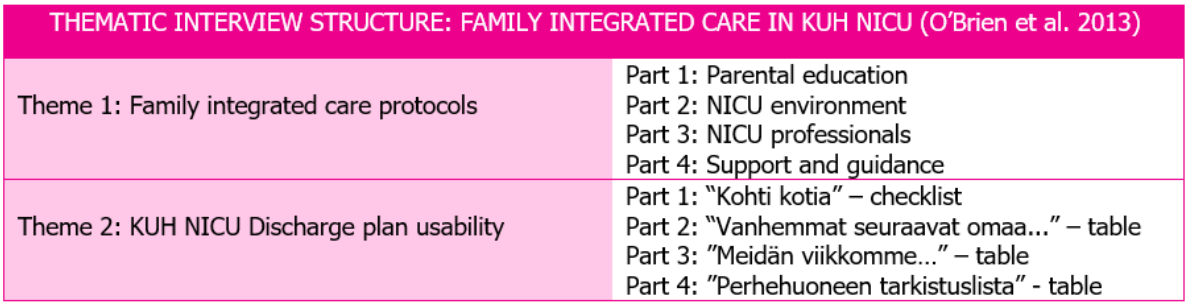
Qualitative analysis is typically divided into either inductive or deductive analysis. The chosen analysis method depends on the logic of the reasoning, whether one wants to think from the individual to the general aspect, or vice versa. Inductive analysis is made from individual to general reasoning and deductive analysis from general to individual. (Tuomi & Sarajärvi 2018, 80.) With inductive analysis the conclusions are drawn using the collected material as an aid. Data orientation is indeed one of the characteristics of qualitative research. A dialogue between theoretical knowledge and collected material is very typical of qualitative research. Theoretical framework is seen as a helpful tool to perform the research itself. The research objectives are often presented in the form of research questions. Only two or three research questions should be asked, so that the delimitation of the topic remains clear. Interviews are often used to acquire material, either individually or in groups, or in addition to these, observation is one option to collect data. Finding and presenting different perspectives is seen as significant in research and the analysis leads to rich material. (Juuti & Puusa 2020b, 9-14, Puusa & Juuti 2020, 73-74.) In this thesis, qualitative research was chosen because the goal was specifically to collect experiences and views of NICU families and nurses. The inductive analysis method was used as the experiences of individuals were gathered and to form more general statements. Qualitative research approach also was seen to compliment the service design methodology and its stages in this thesis.

Thematic interviews are a good method when the aim is to collect people’s experiences and interpretations of events and experiences. The focus is built around themes that are closely connected to the occasion in question. A thematic interview is described to be a semi-structured interview method. The structure comes from the fact that the themes are the same with all interviewees. However, unlike structured interview, thematic interview is not as disciplined, and it does not have a strict form and order of questions. The main point of thematic interview is instead of answering to strict questions, to flow within the chosen mainline themes. This gives the interviewees more freedom to speak up and gain active role in the interview. All interviewees should have subjective experience about the researchable occasion and the researcher strives to collect their experiences. The interview is seen as a two-way interactive situation. The interviewer’s ability to build trust and sense the interviewee’s feelings is important to be able to lead the interview around the chosen themes. (Hirsjärvi & Hurme 2022, 45-48, 53.)

In this thesis thematic interviews were chosen as a data collection method, since in large perspective it was the goal to deepen the understanding of the current care protocols in use in KUH NICU as an entity. Before the interviews it was known that the discussions might raise multifaceted answers as the interpretations and experiences are subjective. The goal was to create a compaction, representing all views and opinions, while clarifying the developmental needs from the viewpoint of the current service users, parents. (Hirsjärvi & Hurme 2022, 32-33.)

The parent interview was completed through a Teams conference call. Both thesis workers were present. The interview was recorded with two mobile devices simultaneously to prevent any data loss. Three of the nurses' interviews were completed through a Teams conference call and three face-to-face. Some of the nurses were interviewed with both thesis workers present together, and some were interviewed solo by one of the thesis workers. All six interviews were recorded on a mobile device. When both thesis workers were present, and the recording was done with two separate devices. Using a separate recording device during a thematic interview enhances the interviewing process and frees the interviewer from using paper and pen to record essential notes. (Hirsjärvi & Hurme 2022, 93.) All interviews were completed successfully with the pre-set themes discussed. The interviews were transcribed into Word documents without any personal data or notes that could result in recognition of the person in question.

Planning the mainline themes is the most important part of the research plan when using thematical interviews. The basic concepts start to form when researching the theories and existing research data surrounding the chosen phenomena. For the interviews, there is no need to form a detailed catalogue of questions. The focus is to create a structure of the chosen mainline themes guiding the interview. When planning the interviews, the first thing is to recognise the problem or research task and the main concepts related, based on the existing research data. Those main concepts can help forming the main categories for the thematic interview questions itself. The main thing in a thematic interview is, that all questions are open. The type of the questions can vary, and they can be reflecting the interviewees opinions or be simply fact based. (Hirsjärvi & Hurme 2022, 66-67, 108-109.)



THEMATIC INTERVIEW STRUCTURE: FAMILY INTEGRATED CARE IN KUH NICU (O'Brien et al. 2013)	
Theme 1: Family integrated care protocols	Part 1: Parental education Part 2: NICU environment Part 3: NICU professionals Part 4: Support and guidance
Theme 2: KUH NICU Discharge plan usability	Part 1: "Kohti kotia" – checklist Part 2: "Vanhemmat seuraavat omaa..." – table Part 3: "Meidän viikkomme…" – table Part 4: "Perhehuoneen tarkistuslista" - table

Figure 5. The thesis thematic interview structure

In this thesis project, the first theme for the interviews was subcategorised using the four sectors of the FICare model (O'Brien et al. 2019, see Chapter 4) because the model is a comprehensive overview of the most important factors in successful family integrated care. The goal was to study if in KUH NICU all those factors are implemented to the care productively (Figure 5). The second theme was about KUH NICU discharge plan integration and characteristics. The discharge plan was seen as natural part of the FICare protocols in KUH NICU. The implementation of this second theme was supported by visualisation. The purpose was to have printed information related to the current discharge plan (see Appendix 5) in front of the interviewees so more detailed opinions about the program and thoughts about the material itself could be brought up and discussed.

6.2.2 The content analysis

Content analysis was performed for the material collected from the interviews (see Figure 6). There are several ways to start analysing the material after the initial interview recordings. In this thesis, the chosen way was to transcribe the full audio material from the interview dialogues into Word document form. Each interview had its own separate document. Transcribing the material first is more common than making conclusions straight from the interviews. Also, transcribing works well when there is a lot of material to be analysed. (Hirsjärvi & Hurme 2022, 145.) A single interview lasted an hour on average, and it took approximately five hours to transcribe each interview.

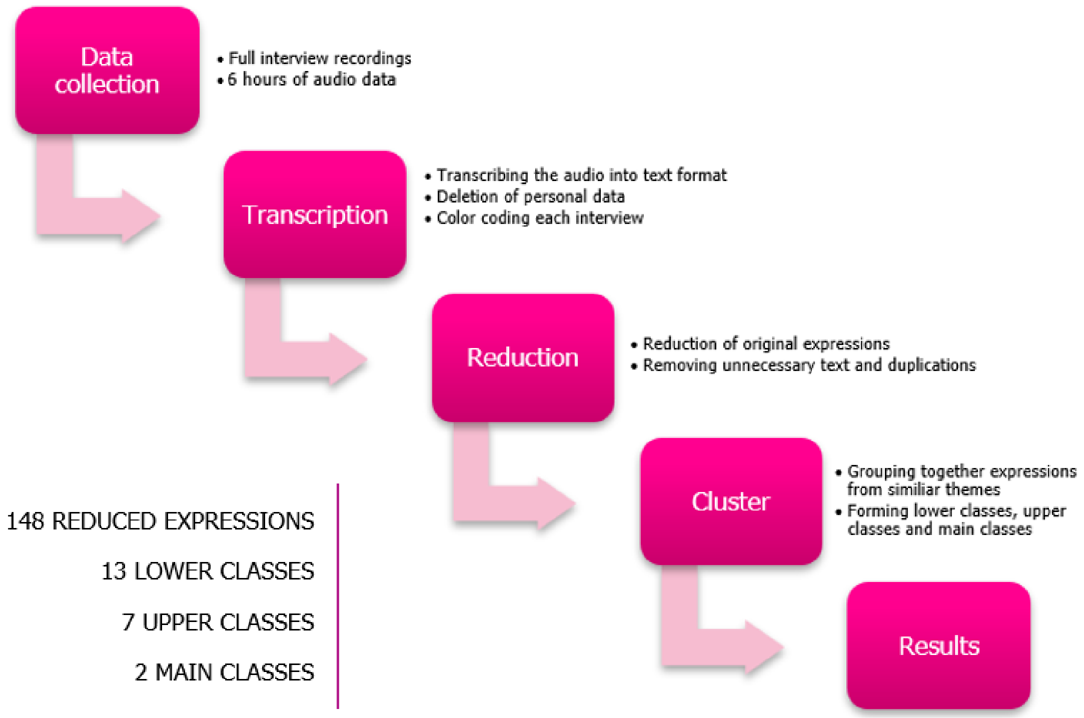


Figure 6. The thesis research content analysis

Each of the interviews were coded with different colours. This was done to make it easier for the thesis authors to detect similarities between interviews in relation to the themes. The thesis authors aimed to authenticate, that the nurses have common understanding and similar opinions of matters related to FICare practices in KUH NICU. APPENDIX 9 shows an example of nurses reporting about the named nurse system. It shows the nurses had similar thoughts about the theme. Also, it verifies the named nurse theme was discussed in all interviews.

According to Tuomi & Sarajärvi (2018, 122-123), the content analysis process starts with reduction of the material, moving to clustering the collected material and leads to creating theoretical concepts. Qualitative analysis aims to build a comprehensive picture of the studied phenomenon and present it in new perspective (Hirsjärvi & Hurme 2022, 151). Before starting the actual content analysis, the analysis unit must be selected. It can be a single word or phrase or a set of thoughts. The research task itself and the quality of the data mainly determine the chosen analysis unit. (Tuomi & Sarajärvi 2018, 122-123.) In this thesis the analysis unit is FICare in KUH NICU, which describes both research tasks, and the goal of the thesis. Originally, there were more than two themes included in the interviews solely about digitalisation (see Appendix 4). However, the content of the interviews was very rich with discussion of the family integration and discharge planning included. The content analysis was made based on the two research questions and in this way the material of the interviews was constricted to meet the thesis purpose and goals better.

The first phase of the content analysis is reducing the original data, the intention is to remove all material outside the scope of one's own research from the material. The reducing can be done by searching interpretations concerning the research questions. The aim is to find original interpretations and list them in a table. Second is the clustering phase, where the concepts and expressions describing similarities are sought. Interpretations that describe the same subject or phenomenon under research are grouped into classes. The original interpretations that are simplified in the reduction phase, first form lower classes. Combining of lower classes leads to the formation of higher classes. The classes are named with a descriptive concept. The last phase of content analysis is abstraction, conceptualisation. The purpose of this phase is to extract relevant information and generate theoretical concepts. Abstraction is continued by combining classes until conclusions are reached. As a result of the analysis, the research question has been answered. (Tuomi & Sarajärvi 2018, 123-127.)

7 RESEARCH FINDINGS

The six nursing interviews resulted in an analysis of how family integrated care protocols in KUH NICU work now as viewed by experienced NICU nurses. During all nursing interviews it became clear that the one single most important theme allowing successful family integration is nurse led parental guidance. The one interview completed with a former NICU parent supported this view. In KUH NICU nurses support and guide parents throughout the care paths, and in most cases the care path starts from the time the mother is hospitalised prior to a possible preterm labour in the women's acute care centre located next to the KUH NICU. The other significant theme in the analysis was related to the actual hospital environment and the care and support protocols the environment provides. KUH NICU has existed in its current form since 2015, offering single family rooms to all families whose baby needs intensive care. KUH NICU is the first NICU in Finland to apply a family integrated care model in a complete single-family room unit.

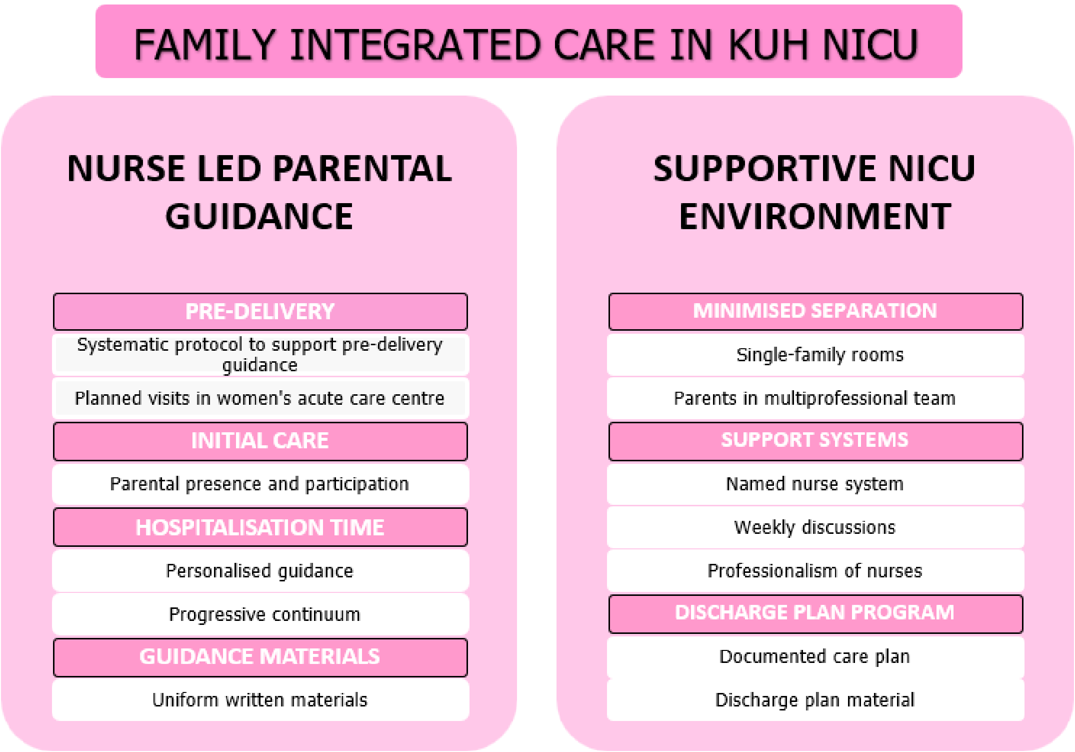


Figure 7. Family integrated care in KUH NICU

This chapter will present the results of the content analysis (Figure 7). The two main classes, nurse led parental guidance and supportive NICU environment are discussed separately. Altogether there were 13 lower classes recognised, and they are portrayed in white in Figure 7 below their signed upper classes. The lower classes formed a total of seven upper classes and were further divided into two main classes. As a part of the results, from each lower class there are figures containing simplifications from the original content analysis to highlight the most important notifications made by the interviewed nurses. The one interview completed with a parent is not part of the content analysis since the results of one interview cannot be generalised. However, the following results will provide some insights of that interview as well. The interviewing structure with the parent and the nurses was the same, and on many occasions, the parental and nursing views of family integrated care supported each other.

7.1 Nurse-led parental guidance

The interviews with nurses concluded systematic and personalised parental guidance are key components in successful family integrated care. The work and collaboration with families in KUH NICU start before the expected preterm birth and continues throughout the hospitalisation time and care path. In KUH NICU there is a pre-delivery guidance protocol in place that includes visits with parents while in women's acute care centre and introducing the NICU facilities. In initial care (care given right after birth) parental participation and presence is seen as an important factor and parental participation is encouraged and guided by nurses continuously during the care. To support given guidance there is a lot of material given during the care path at proper times. The key challenges affecting the given guidance that came up during the interviews were mostly related to hurry or inadequacies in resources. Some challenges were related to the guidance material itself, and it was expressed by the nurses that more appropriate design instead of large quantities of separate sheets should be discussed.

7.1.1 Pre-delivery

In the interviews nurses reported there is a written protocol for systematic pre-delivery guidance (see Figure 8). The protocol includes a visit from a NICU nurse to the women's acute care centre when a mother is hospitalised because of a risk for preterm birth. Usually, a neonatologist also visits the parents. Additionally, a social worker and a crisis worker can also visit in the acute unit. Nurses also said a part of the pre-delivery guidance is to introduce NICU facilities to the parents. When a mother in acute risk of preterm labour is hospitalised, the women's acute care centre shift manager informs the shift manager in NICU as soon as possible. Once a week, professionals from both the women's acute care centre and NICU gather for a meeting, and the information of possible preterm births is shared there. The resources and optimal timing for the pre-delivery visit and guidance is discussed and arranged according to the family's needs.

It was discussed during the interviews that an unexpected preterm birth always creates a challenge for the pre-delivery guidance, and it was pointed out that sometimes parents are left without any preparatory information from the NICU professionals. Nurses suggested this may be due to the acute nature of the preterm birth, but also sometimes because of lack of resources in NICU. In the parent interview, the parent mentioned that someone had told them there would be a visit from a NICU professional, however that did not happen before the birth.

It was also mentioned several times during the nurses' interviews that recently there has been no specific group focusing on the pre-delivery visits and NICU facilities introductions. This was seen as a challenge and nurses felt the protocol of what is to be discussed during the visits is not clear to all. The nurses felt focusing the pre-delivery guiding to a specific nurse group would help increase codirectionality and guarantee more systematic guidance.

Systematic protocol to support pre-delivery guidance

- Includes visits from NICU staff to women's acute care unit and introducing NICU facilities to the parents
- Acute nature of preterm birth sometimes prevents families from receiving guidance
- Focusing specific nurse group on giving guidance increases codirectionality

Figure 8. Pre-delivery guidance

In the interviews nurses expressed a good quality visit to women's acute care centre is time consuming (see Figure 9). They pointed out that there should be a proper amount of time to be genuinely present for the families without hurry, and time to answer and discuss the questions parents might have. One nurse pointed out they need at least one hour to discuss all the important matters without haste. Nurses also said that at first parents might not have any questions at all, and just after the NICU nurse starts explaining and giving guidance, the discussion prompts parents to demand more information. This was suggested to be because of the unique nature of the situation – the parents do not necessarily know what to ask and what to expect and are relying on professional support.

Planned visits in women's acute centre

- Visits are not always organized systematically
- Good quality visit is time consuming
- The guidance and information received without haste before birth is reflected to parental participation after birth

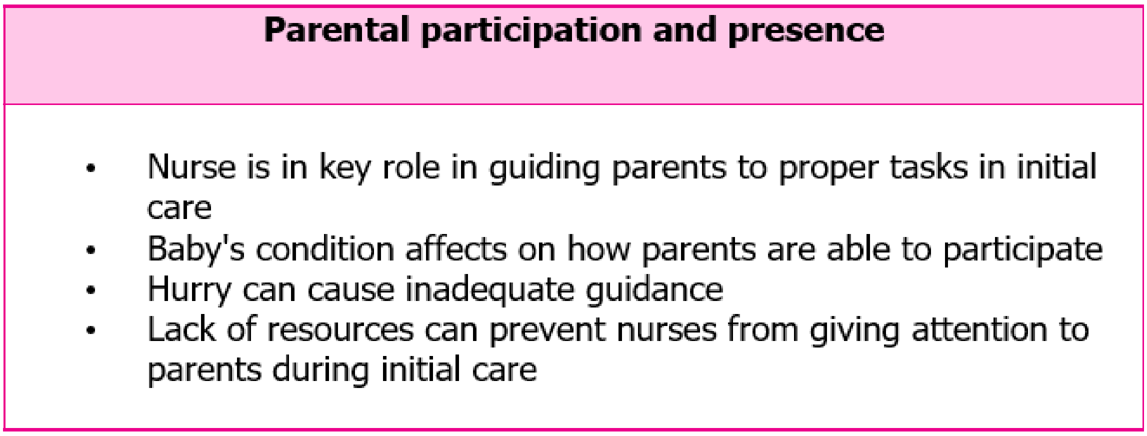
Figure 9. Visits in women's acute centre

On the other hand, nurses reported that sometimes parents do have a lot of questions to ask, and the nurses also said how parents have expressed their gratitude for the pre-delivery guidance and information they got. In the parent interview, the parent said they were somewhat disappointed that the planned visit from a NICU professional did not happen. The parent said the threat of a preterm delivery was initially a scary thought, and it left an unsafe and worrying feeling. The parent also reported they assumed the NICU professionals might be busy and, that they understood the circumstances and resources did not allow a visit at that time. The nurses mentioned during the interviews that mothers who are for example in bed rest in women’s acute care centre because of a threat of preterm labour, seem to be very receptive and ready for receiving information when the situation is not acute. The nurses expressed that the pre-delivery guidance and information given seems to influence the parent’s ability to participate in the care of a premature baby.

Nurses said that the visits to women’s acute care centre are not always organized systematically. It was thought to be possible that because of this the content of the guidance might be of uneven quality. In the interviews, all nurses mentioned that the same things should be discussed pre-delivery with all parents. Those things included educating parents about benefits of breastfeeding, the importance of kangaroo care and skin-to-skin contact, parental participation and continuous presence and general information about how KUH NICU as an environment works. The nurses mentioned systematically three pamphlets that should be given to parents during the visit: NICU information sheet, a guide for breastfeeding and milk pumping and a guide about kangaroo care.

7.1.2 Initial care

The first moments of initial care of a preterm baby are executed in the women’s acute care centre facilities. The baby is cared for in a specific procedure room next to the labour rooms equipped for the NICU professionals. The partner of the mother giving birth can be present in the room during the care. As soon as the neonatologist determines the situation to be stable enough, the preterm baby is transferred inside an incubator to NICU, usually to a family room. Parent can stay with the baby the whole time. Initial care then continues in the family room.



Parental participation and presence

- Nurse is in key role in guiding parents to proper tasks in initial care
- Baby's condition affects on how parents are able to participate
- Hurry can cause inadequate guidance
- Lack of resources can prevent nurses from giving attention to parents during initial care

Figure 10. Parental participation and presence

Nurses said during the interviews that the parents are encouraged to participate in the initial care from the start (see Figure 10). All the interviewed nurses saw this as an important matter. Parents are encouraged by the nurses to touch the baby and stay near to encourage bonding. In the interviews nurses expressed that efforts should always be made to find a suitable way for parents to participate in the initial care. Nurses said that for this to happen it requires a lot of time, maneuvering and articulation from the NICU nurses at the beginning. The parent said during their interview that they were especially careful, and that they did not necessarily even understand to ask for certain things. Looking back to those moments in initial care, the parent reported that knowing what they know now they might have been more active in demanding and asking for help. The parent said that they were scared at the beginning, and that it came as a surprise how soon it was for example possible to hold their baby. The parent wanted to highlight the meaning of the initial guidance given by the NICU staff, because as parents, they relied completely on what professionals have told them to do.

It was brought up by couple of nurses that in their opinion family integrated care during initial care does not necessarily translate into participating in everything but finding proper ways to let the parent stay near the baby. Nurses reported that hectic conditions like hurry and the baby's critical condition affect on how parents can participate in the care. Nurses also said hurrying can cause inadequate guidance, since during critical situations the nursing resources go primary to the baby, not the parent. The nurses expressed repeatedly that from time to time there are not enough resources to give proper attention and support to the parent.

7.1.3 Hospitalisation time

During discussions with the interviewed nurses, the overall thought was that parental guidance is one of the key tasks of nurses' daily work in KUH NICU. The nurses said that there are a lot of nurses working in KUH NICU, and each nurse has their own way of working. Overall, the nurses reported that everyone's individual skills are and should be respected as well as the unique parental needs and situations, and the comprehensive goal is to give uniform guidance. The key elements about personalised guidance are presented in Figure 11 below. The nurses said the different ways of working influence sometimes how the guidance is given to families. Some nurses expressed in the interviews even the personality of the nurse and personal opinions may sometimes influence the guidance given, though this was thought not to be professional and to be avoided. It came up during the nurses' interviews some nurses might find some topics less important on a personal level and therefore do not concentrate or press on that topic when guiding parents during hospitalisation time.

Personalised guidance

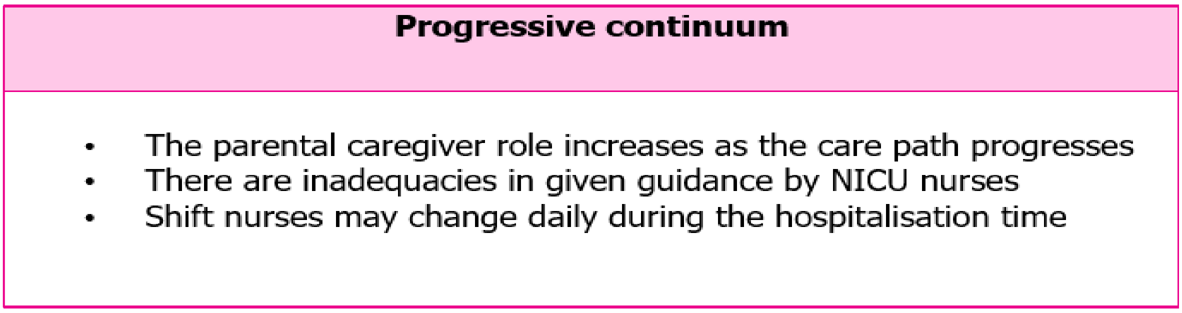
- Good guidance and reporting take time
- Special skills and education of NICU nurses should be utilised more
- Respecting families' individual needs and habits is important

Figure 11. Personalised guidance

The different styles and ways of guidance was observed also by the interviewed parent. The parent said they understand different people might guide with different styles; however, they also reported that this caused confusion and that they respectfully gave this feedback. On the other hand, the parent also said it gave them an opportunity to see different ways to do certain things. The parent also said many of the nurses mentioned to the parents they realise the number of different styles the parents might observe during their care path. The nurses said that personalised guidance is highlighted during the hospitalisation time, and the guidance should always come from family's needs first. The nurses pointed out not every family is able to receive the guidance in the same manner and time as others. This depends a lot on how the care path of the preterm baby is evolving, and how critical the situation is.

In the interviews, nurses said that special skills and education should be utilised more than it is done today. The interviewed nurses said that for example, the utilisation of professional skills of breastfeeding counsellor's should be enhanced more than it currently is in the guidance of a premature baby's breastfeeding. It was also pointed out how important it is to report properly about the given guidance orally and to the electronic patient information system to prevent miscommunication. The nurses reported that unfortunately the lack of time sometimes causes incomplete record keeping. Also, discussion about alternative guidance material was discussed, audio-visual material like video cannot replace face-to-face guidance, but it could enhance the guidance.

The nurses said the content of the guidance expands as the premature baby's hospitalisation time and care path proceeds (see Figure 12). More content concerning parental involvement is provided and their activity in the care of their baby is increased as the baby is growing. The nurses thought guiding parents to be a continuum. The nurses were aware of the benefits that a systematic approach to guidance and support give; however, they also suggested there the information is incomplete. All interviewed nurses reported inadequacies with the given guidance. The same feedback was reported in the parent interview. The parent pointed out how frustrating it felt to be guided differently by each nurse. The fact that shift nurses changed a lot, even daily, during hospitalisation time was noticed. The views of the nurses and a parent in interviews agreed that this often leads to ambiguities and confusion among parents and the nurses.



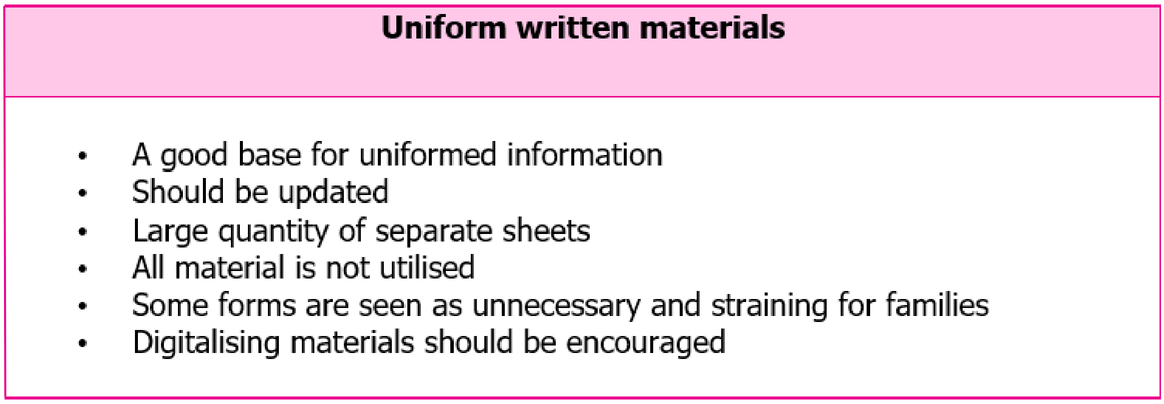
Progressive continuum

- The parental caregiver role increases as the care path progresses
- There are inadequacies in given guidance by NICU nurses
- Shift nurses may change daily during the hospitalisation time

Figure 12. Continuum of guiding

7.1.4 Guidance materials

KUH NICU has a large quantity of existing written guidance material. Materials come as ready pamphlets or written sheets printed from computers. The quantity of separate printed materials came up in the interviews repeatedly, and with all nurses (see Figure 13). The nurses agreed long written pamphlets might not be most optimal form of guidance material. The nurses agreed the written material provides a good base for uniform information, yet the large quantity might burden the families unnecessarily. According to the nurses, the material is given piece by piece during the hospitalisation time. Some of the pamphlets and sheets seem to contain inconsistent information. The nurses said newer employees might not have even seen all the materials let alone used them for parental guidance. All together printed information was seen as an outdated way to provide uniform information. Nurses expressed that some of the materials are left completely unused. The nurses saw digitalisation of guidance materials as a good way to increase systematic guidance in the future. The consensus was that it would be more appropriate to have the material "in one place" instead of providing scattered materials which can – according to the interviews – be in some cases outdated.



Uniform written materials

- A good base for uniformed information
- Should be updated
- Large quantity of separate sheets
- All material is not utilised
- Some forms are seen as unnecessary and straining for families
- Digitalising materials should be encouraged

Figure 13. Uniform written materials

7.2 Supportive NICU environment

Since 2015 KUH NICU has offered single-family rooms to all families with a baby in need of intensive care. There is barely any separation time between parents and their baby during the hospitalisation time because of the family integrated care culture. Siblings and extended family members can visit and stay in the unit during hospitalisation. Part of the culture is including parents in the care decision making process. The family integrated care protocol in KUH NICU includes a named nurse system, a specific nurse assigned to a specific family. The goal is of the named nurses is to prioritise to care for their designated families through the care path. Their role in supporting and guiding the parents is more significant than other changing shift nurses. KUH NICU applies a specific discharge plan (see Appendices 5-7) in the family integrated care protocol. Unlike the name might suggest, discharge planning is supposed to start, depending on the condition of the premature baby, as early as in the first weeks after birth and continue progressively throughout the hospitalisation time. According to the plan, parental skills, and readiness to care for their baby should be encouraged from the very beginning and monitored during the care path.

To maintain continuum, weekly discussions are a part of the program. Weekly discussion is a discussion where ideally both parents, the named nurse and a named doctor participate together. It is meant to be a more in-depth meeting, and an opportunity for the parents to ask questions related to the care of their premature baby in an unhurried, scheduled conversation. The discussion goes through childbirth and the postnatal period up to the present. In addition to this, the named doctor talks about the plans for the near future in terms of care.

Single-family rooms as a NICU environment offer privacy and a unique setting for parental guidance and empowerment. The main challenges mentioned during the nurse interviews were related to families becoming too keen on the hospital routines instead of listening and observing baby’s schedule first, and about the family room being quite restless at the beginning of the care path. The nurses expressed inconsistency in the named nurse system as well as carrying out the weekly discussions. Discharge care plan related material was thought to be only partly in active use. The nurses highlighted the importance of experienced NICU nurses and deeper understanding of the premature baby’s care path in parental support.

7.2.1 Minimised separation

The NICU nurses said in the interviews minimising separation between the preterm baby and the parents is already today’s mode of operation. The aim is to bring together the newly formed family and keep parents always informed about their baby’s condition from the very beginning. After delivery, the whole family is transferred to the family room in the NICU (see Figure 14). The nurses stated settling into the single-family room is not always a straightforward process, and when a premature baby is transferred to the family room after initial care, the environment in the room might be restless because of the medical attention a prematurely born baby needs. It was reported that typically the first weeks after a premature baby is born, there is a need for the shift nurse to visit in the family room almost around-the-clock depending on the baby’s overall condition. The nurses mentioned in the interviews that when they see parents nesting in the family room, for example bringing some items and clothes from home, it conveys to the nurses a sense of felt security and safety. The nurses said it varies when and how this happens, if at all. The nurses expressed a belief settling in the family room and finding routines are a part of the family’s wellbeing. The parent had a similar view and told the belongings that could be brought from home, books, and clothes, made it a bit easier to settle to the room.

Single-family rooms

- Parental participation and independency increase as the care path progresses
- Settling to the family room is not always easy
- Families can stay caught up in the hospital's routines for an unnecessarily long time

Figure 14. Single-Family rooms

In the interview with the parent, they said they settled surprisingly well to the family room. The parent felt it took time to come to terms with the fact that the single-family room was their "home room". They also said that it wasn't until getting to the family room that somehow all the feelings started coming to surface. The parent explained that in that moment, arriving to the family room, it just became reality that they are there in NICU as a family.

In the interviews nurses said that in the beginning of hospitalisation of a premature baby many care tasks like medication and feeding are clocked and scheduled by the care professionals, and that parents can stay caught up in the hospital's routines unnecessarily long as the baby's care path proceeds. The parent reported during the interview that you cannot escape the reality of a hospital environment since you are surrounded by things like hospital beds and incubators.

The nurses said the leap from scheduled hospital routines to practising more baby-phased, homelike routines takes sometimes a long time with growing premature babies. The nurses agreed that parental participation and more independent activity in the care of the premature baby should increase during the hospitalisation time. There was discussion with the nurses that it is the responsibility of parents to satisfy the baby's basic needs such as comforting and nursing the baby, and nurses should be able to encourage parents to do so.

Nurses reported consistently that parents are seen as a part of the multiprofessional care team. The parents are encouraged to participate and express their opinions in planning the care of their premature baby (see Figure 15). Some of the nurses were suspecting hurry can affect the willingness of a parent to ask things that might worry them about the baby's condition or care related questions overall. Also, nurses believed parents may sense the rush of the unit and leave the questions unasked. The nurses said that their view is some of the families may simply settle with the guidance given by a health care professional, but that some have the courage to ask and demand more detailed information about the care. The nurses said the courage usually comes after families have stayed longer in the unit and have already familiarised themselves with the routines. The nurses thought this to be a sign of the empowerment as a parent and increased readiness to take care of their baby. The nurses reported it is important sign of an attachment relationship between a premature baby and a parent.

Parents in multiprofessional team

- Parents are encouraged to voice their opinions and wishes
- Hurry can affect on parents' sensitivity to ask nursing staff care related questions
- Growing to be an empowered parent can take a long time

Figure 15. Parents in multiprofessional team

7.2.2 Support systems

Family integrated care protocol in KUH NICU includes a named nurse system, whose role in supporting and guiding the parents is more significant than other changing shift nurses (see Figure 16). In the nurse interviews the nurses described the named nurse to be a trustworthy professional that families can confide in about difficult matters. Nurses said the families tend to grow attached to their named nurses with whom the relationship is different. All the interviewed nurses had experiences from long-term care relationships as a named nurse for a prematurely born baby and long professional careers as NICU nurses. All interviewed nurses expressed a belief the named nursing system tends to be more systematic and intense at the beginning of the care path during critical care. Nurses said this is mostly because experienced nurses are present during initial care on the first days after birth and usually the attachment and the decision to start the named nurse care relationship forms naturally.

Named nurse system

- The role is seen significant
- Not systematic with all families
- Named nurses rarely discharged their "named" preemies

Figure 16. Named nurse system

When the care path evolves and the baby is in stable condition, the named nurses might be needed in critical care of other patients, or for initial care of other premature babies. The nurses reported it is rare for an experienced nurse to be able to discharge a premature baby, whose named nurse they were at the beginning. When prematurely born babies are closer to being discharged, they can be cared for by newer nurses, since the babies are in more stable condition and most likely parents are taking care of some of the daily needs more. This creates a loop, where the named nurse care relationship fades as the planned discharging date approaches. The nurses said families sometimes ask why their named nurses are on shift but not assigned to them.

The parent said during the interview that during their care path at first, they did not have named nurses. The parent reported they remember thinking what does "named nurse" mean written on the board that was placed inside their family room, next to the door. The parent said for some time there were no names following. Then one day, one nurse asked permission to be their named nurse and eventually, they ended up having three named nurses during their care path. The parent liked this system, and there was always a certain anticipation whether the named nurse would be with them on shift. The parent told one of the named nurses this helped them to move forward towards home with her guidance and participation. With this particular family, the named nurse system was carried out well.

The interviewed nurses' view was that weekly discussions are not held regularly. However, some of the nurses said there are attempts nowadays to pay more attention to the discussions so that they would take place regularly. The nurses said the discussions should be planned and arranged together with the family, a named nurse, and a named doctor (see Figure 17). The nurses believe the named nurse system is important factor not only for the care relationship, but for the weekly discussions to be executed properly. The nurses felt the discussions should be planned so that the named nurse is able to participate in the discussion. The nurses also mentioned that for this to work, it would be important for the named nurse to be able to participate in the care regularly, and throughout the care path.

It was the nurses' view in several interviews that parents do not always speak up or express their own thoughts freely during the discussions. The nurses felt this is also why the named nurse should be present in the discussion as an advocate for parents and the premature baby itself instead of whoever happens to be on shift. The nurses and the parent agreed on many occasions the weekly discussion can come up unexpectedly and without a prior notice. It was the view of some of the nurses and of the parent, that many times it was up to the doctor's schedule. The parent said that usually the nurse present during their weekly discussions was not their named nurses. The nurses said in the interviews that reporting would also be important after the weekly discussion, so it is visible for the whole care team what was discussed. The nurses pointed out that incomplete reporting of the insights from the discussion sometimes causes miscommunication with the families.

Weekly discussions

- Should be planned according to individual needs
- Are not always arranged
- Incomplete reporting of the insights causes miscommunications

Figure 17. Weekly discussions

The interviewed nurses pointed out that an experienced nurse can face families genuinely and be present even in the challenging situations. The nurses' view was the experience and professionalism provide the sensitivity to face families in different situations experienced while staying in NICU and helps in sensing the parents' ability to cope within the neonatal intensive care (see Figure 18). An unhurried presence with families was seen as important, just to be present with the family and for example, discuss the family's wellbeing or other issues the family wishes. The nurses said experience gives deeper understanding of why things are done in certain way. The nurses believe a skilled nurse can stimulate and involve parents to participate in the care of a premature baby, and perhaps push them more smoothly to step outside of their comfort zone.

Professionalism of nurses

- Professionalism gives sensitivity to face families genuinely
- Experience gives deeper understanding of why things are done
- Skilled nurse can encourage and involve parents
- An unhurried presence with families is seen as important
- Increasing peer learning was seen important

Figure 18. Professionalism of nurses

The need for increasing peer learning was a topic that was pointed out in several nursing interviews. The nurses said that working in pairs formed by an experienced and an unexperienced nurse was seen as an efficient way to learn. Unfortunately, a busy work environment and lack of resources were reported to have a negative effect on peer learning. The nurses said that to the newer nurses it might be challenging to learn by doing when parents are actively participating in the care of the premature baby.

7.2.3 Discharge plan program

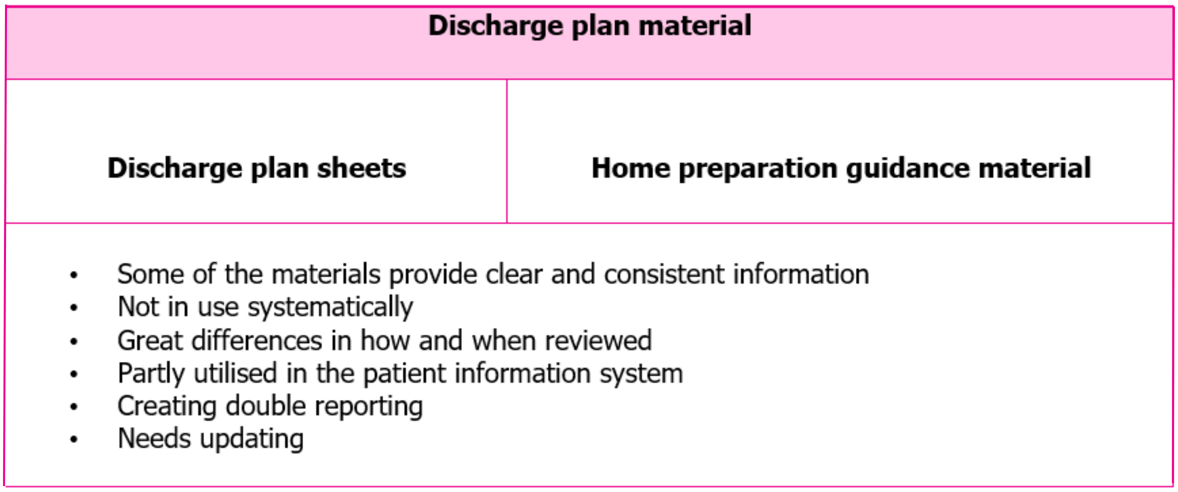
The discharge plan program is probably the most extensive part of the family integrated care in KUH NICU, and a lot of the work protocols in KUH NICU are initially attached to the discharge planning. The discharge plan program includes the above-mentioned weekly discussions, as well as the pre-delivery guidance protocol. The separate written sheets and guidance material are only a part of the discharge plan (see Appendices 5-8; Figure 19). The KUH NICU discharge plan should bring all the protocols together seamlessly and provide a clear and consistent care path. Discharge planning starts very early during a premature baby's care, when the condition of the baby and overall situation with the family allows it. Nurses agreed in the interviews the discharge requires a lot of planning and a systematic approach to be successful. In the interviews nurses reported some inconsistencies in carrying out the discharge plan.

Documented care plan

- Aims to be visible and ongoing process for the families and multiprofessional team
- Baby's condition affects on how and when discharge is discussed
- Usually discharge planning should start when preliminary discharge date is set
- The roles and responsibilities among professionals in relation to discharge planning vary
- Partly utilised in the patient information system

Figure 19. Documented care plan

The discharge plan material consists of printed papers, that should be in use with all families during their care path in NICU (see Appendices 5-8; Figure 20) and of a home preparation guidance material package given to the parents closer to the discharge date. The home preparation material includes guidance on how to prevent baby's head from unwanted shaping, sleeping safety and crib death prevention, and emergency instructions in case of suffocation or milk aspiration. The discharge plan sheets are meant to visualise for the professionals and the parents how the care path and parental readiness is evolving, and to help parents to plan their days in NICU based on their own needs. The sheets were a part of the thesis research and each interviewee got to see the sheets as a part of the thematic interviews, so they could provide more detailed feedback of how the sheets are utilised.



<table>
<tr><th colspan="2">Discharge plan material</th></tr>
<tr><th>Discharge plan sheets</th><th>Home preparation guidance material</th></tr>
<tr><td colspan="2">• Some of the materials provide clear and consistent information
• Not in use systematically
• Great differences in how and when reviewed
• Partly utilised in the patient information system
• Creating double reporting
• Needs updating</td></tr>
</table>

Figure 20. Discharge plan material

The nurses agreed in the interviews some of the material related to discharge planning provide consistent and usable information. However, when going through the discharge plan sheets with the nurses during the interviews (see Appendices 5-7), they almost unanimously pointed out the sheets are not in regular use at this moment in KUH NICU. Reasons given for this were for example, that not all nurses find the sheets useful in every day working or, the families are not told to fill the sheets in the first place anymore. Some nurses found some of the material not usable as it is in paper sheets. Altogether, the material seemed to be at least partially forgotten. From all the sheets related to the Discharge planning, two sheets seemed to gain the most positive notes from the nurse interviewees. These two sheets were a checklist called "Kohti kotia", which means "Towards home", and it works as a checklist for all the things needed to be taken care of before discharge, and a care list for the parents to fill when they are caring for their premature baby independently in NICU (see Appendices 5, 8).

The nurses said that despite the "Kohti kotia" checklist is in use somewhat inadequately, they found it to be informative and a good compaction of the care path in KUH NICU. It came up that the checklist can be found in the patient information system also, resulting partially in double reporting. The checklist in the patient information system is not the same as the paper form, but the nurses said it is being used for the same exact purpose. The nurses felt even though the check list is meant to be for the parents also, this list in particular serves more the professionals than the parents. The nurses' view was that the checklist is rarely utilised for example during weekly discussions and some of the nurses confessed to forgetting to even start filling this list on some occasions with the families, when a new care path in KUH NICU starts. Nurses mentioned the checklist like "Kohti kotia" could be a more significant part of the discharge planning with updates to the content itself. For now, the checklist recognises information given before delivery, initial care, hospitalisation time and the preparations made close to discharge date. One nurse pointed out giving all this information on a sheet could be distressing for the parents and exposing them to all the things that lay ahead on their NICU journey is not necessarily always a good thing.

The care sheet (see Appendix 8) was praised and liked by all the interviewed nurses. Generally, the care sheet should be placed into the family rooms for the parents to fill out whenever they start caring for their baby independently. The nurses felt this sheet clarifies to the parents well what is expected of them as caregivers, and it is a good way of reporting the care and feeds. The nurses had experience, that almost all families use the sheet. The nurses told systematically that they use the written information on the sheet and transfer it to patient information system recordings, so the data is also in the computer, in the baby's chart. Two of the interviewed nurses talked about a family, who during their KUH NICU time downloaded an application including similar fillable boxes as in the care sheet provided at the unit. They could record feedings and diaper changes and give this information from the application then to the nurses.

The nurses told "Meidän viikkomme perhehuoneessa" and "Vanhemmat seuraavat omaa oppimistaan" lists (see Appendices 6-7) are not in active use at KUH NICU. The correct place for them to be visible would be inside the family room on a specific cabinet door, where professionals and parents both can see them. "Meidän viikkomme perhehuoneessa" is about the family writing down and planning their own weekly schedule. There is a box for daily program and goal, scheduled labs or scans for the baby, discussions, other activities, and breastfeeding/milk pumping. The sheet also asks parents to provide a smiley face according to how the day was. Nurses told this sheet could be beneficial in their own work if families were filling it. They could not name specific reasons why the sheet is not in use anymore, mainly they explained it might be just forgotten. The same was said about "Vanhemmat seuraavat omaa oppimistaan" sheet, which was also described by the nurses to be possibly beneficial, if in systematic use, however the nurses told it has not been visible in the rooms in a long time. The nurses were pondering if the families are guided to fill these sheets in the first place. The nurses told this sheet could help nurses in perceiving what the parents can do independently, specifically if the nurse is not familiar with the parents and the baby.

Home preparation guidance material is a part of the discharge planning process in KUH NICU. Of that material the nurses agreed it should be discussed and given to the families no later than one week before the planned discharge date. Some of the nurses brought up that the material should be given earlier than it is done nowadays. The nurses felt there is variation in how the material is discussed with the families and when. Some of the nurses told they have a habit of handing out them to the families and encouraging them to ask questions later if anything comes up. Some nurses said they always go through the sheets with the family before leaving the sheets for them, making sure they really read everything that is on the sheets. It was brought up during the interviews that there have been situations where the family did not remember receiving any material close to discharge. On some occasions, this was because the family forgot they had the sheets in the room, and on other occasions they did not receive the material and it came up only couple of days prior to discharge. The nurses reported overall big differences in how the discharge planning is handled.

The parent brought up in the interview that it brought them additional feeling of safety, when they knew during discharge planning a family worker will be visiting them at home after the discharge. The parent said they had the necessary information and skills to be discharged from NICU, however it felt good to know someone is coming over to check that everything is good and answer to any possible questions at home. All the three discharge plan sheets were unfamiliar to the parent, and they did not recall seeing them during their stay at KUH NICU at all. Of the "Kohti kotia" checklist the parent recognised the things included in the checklist were discussed with them during their stay and felt it seemed to be a good and clear compilation of the NICU care path. The parent felt it might have been easier to see such a checklist, to know what to anticipate. The parent referred specifically to things like named nurse system, which is a part of the checklist. The parent felt if they would have seen such a checklist it may have been easier for them to ask questions about it.

Of the "Meidän viikkomme perhehuoneessa" and "Vanhemmat seuraavat omaa oppimistaan" sheets the parent said they looked nice. The parent felt if they had the sheets during their stay in KUH NICU, it could possibly have helped them to be more prepared for the days. The parent felt that for example preparing for a weekly discussion could have been more composed, if they knew from their visible weekly plan the discussion is coming. Of the "Vanhemmat seuraavat omaa oppimistaan" sheet the parent said it could have been a good way to introduce the parents a mindset of them becoming independent caregivers in the end. Overall, the parent thought the more paper formed sheets there were, the more they were thinking it could become somewhat overwhelming to keep filling out different forms during the days.

8 CONCLUSIONS AND DISCUSSION

This thesis studied how family integrated care protocols appear in the KUH NICU. The FICare model by O'Brien et al. (2013, 1-8) was used as reference, since it gives a good overall picture of what good quality family integrated care should demonstrate. (O'Brien et al. 2013, 6-7.) The goal of family integrated care is to prevent separation between the parent and the baby during hospitalisation time and make it possible for parents to participate in the care of their baby as much as possible in NICU (Ojanperä & Ronkainen 2015; Pettoello-Mantovani et al. 2009). The FICare model's four sectors are parent education, support, HCP (health care professional) education and a supportive environment. The goal of the FICare collaborative model is to support both NICU nurses and the parents of preterm babies and promote parental participation in neonatal intensive care. (O'Brien et al. 2013, 6.)

This thesis also studied how the current KUH NICU discharge plan protocol is engaged into the family integrated care in KUH NICU. A well planned, comprehensive discharge plan can help a premature baby's transition to home and increase parental readiness, when the individual needs of the families are met (Smith et al. 2022, 7-8). According to the recommendations made by Smith et al. (2022, 7-21), discharge planning should start immediately when a baby is admitted to NICU, and the process should continue consistently throughout the hospitalisation time (Smith et al. 2022, 11). KUH NICU currently implements a printed discharge plan program, and the goal was to find out how that plan is actualised.

The thesis research was done with qualitative research approach using thematical interviews as a data collection method, and content analysis as a data analysing method. Thematic interviews were carried out with one NICU family and six NICU nurses. Content analysis was made from NICU nurses' interviews and the results from the NICU family interview were disclosed separately in the results section, as it included considerable similarities with the nurse interviews of the current care practices in KUH NICU but was not enough to be generalised as a part of the content analysis.

The thesis process followed service design methodology and double diamond model working process (Design Council 2023). As a result of the defining phase of the double diamond model, the thesis research results created a foundation for a future digital care path as a novel service model, portraying the current state of family integrated care in KUH NICU. The research results describe the current protocols, well working policies and the challenges related to them.

8.1 Thesis research results

The interviews with the NICU nurses and the NICU family answered to the thesis research questions well. A comprehensive picture was built about the current care practices in KUH NICU and the use of the current discharge plan. From the thesis results, nurse-led parental guidance was believed to be one of the two most significant themes of a successful family integration in KUH NICU. All interviewed nurses described parental guidance to be a continuum from beginning to the end of the care path. The other significant theme supporting family integration in KUH NICU was related to the actual KUH NICU hospital environment with single family rooms, and the care and support protocols the environment itself provides. Besides single-family rooms, the nurses brought up mainly the named nurse system and weekly discussions that should be held with families every week. The nurses also described on many occasions that handling a prematurely born baby's care path in a family integrated way requires expertise and working experience from the NICU nurse. It was described by the nurses that a newly graduated nurse is less likely to be able to support the families as comprehensively as an experienced nurse, since the focus in learning in the beginning is mostly in the medical care and characteristics of a premature baby.

Both themes include several components that support the family integrated care, and those components adapt to the study made by O'Brien et al. (2013, 4-6) well. The main challenges as described by nurses were related to busy work environment, lack of resources and occasional lack of systematicity when it comes to guiding the NICU parents during different parts of their care path. The large amount of printed guidance material is not used in its full potential, although on some occasions they were described by the nurses to be helpful. The main view of the current discharge plan material as described by nurses was, that they are not in systematic use and are partly forgotten. Through the discussions of the pre-set themes, the nurses specifically highlighted the meaning of consistent, systematic prenatal guidance given by the NICU staff. The nurses' view was the prenatal guidance or the lack of influences how the parents can participate in the initial care. Meaning of nurse-led parental guidance was pointed out during every theme (see Figure 5) during the interviews.

It became clear during the nurse interviews the NICU nurses value their job and find it meaningful. They were able to describe the care path of a prematurely born baby and the use of the current discharge plan clearly. Presumably, the nurses were also able to express their opinions freely since the conversations were rich with dialogue in all interviews. Each interviewed nurse was an individual, with a lot of professionalism and knowledge of their field of expertise in neonatal nursing. Each brought their own personality into the interviews but described the characteristics of family integrated care with similar, professional way. The interview with the NICU parent had significant number of similarities from a parental perspective and where the nurses highlighted the meaning of consistent, individual nurse-led guidance to be one of the most important aspects of family integrated care, the parent was grateful of receiving care and guidance throughout the hospitalisation time from the nurses.

The number of participants was not limited, when the thesis research was planned. The thesis authors originally aimed to recruit 5-10 NICU families to gain generalisable information from parental perspective. Although the original research plan was not fully successful, the moderation of the research plan resulted in six good quality interviews with NICU professionals. At the time of the thesis research, approximately 70 registered nurses were working in KUH NICU, and therefore the final response rate was approximately 8,5% of all eligible nurses. However, in thematical interviews even with a smaller number of interviewees the collected data can be rich and enough to form an analysis. A deeper dialogue between the interviewer and the interviewee can lead to richer material. (Hirsjärvi & Hurme 2022, 142.)

8.2 Family integrated care in KUH NICU

In the interviews the nurses said that the parental guidance starts before the baby is born by visiting the family in the women's acute care centre. It was stated repeatedly in the interviews that the protocol is not clear for all. The visits are not carried out systematically, although it has been acknowledged that the content would be more consistent if this were done. Also, it was discussed that a quality visit takes time. The busy, often stressful work environment at NICU may unfortunately have an influence on how comprehensive the visit in women's acute care centre is.

KUH NICU nurses recognise the importance of parental participation well and the partner of the mother is always encouraged to be present during the initial care. Interviewed nurses said that a NICU nurse should always be available to the family during initial care, and that a NICU nurse is in a key role to encourage parents to participate. They raised resource related concerns about being able to support the parents during the initial care, since guiding parents during initial care requires a lot of time, maneuvering and articulation. At the same time, a premature baby's medical care can sometimes require all available resources, leaving the parent temporarily alone in the situation. Parental presence and participation to care should be possible right from the birth of a premature baby. Early skin-to-skin contact after initial care of a premature baby supports the parent-infant closeness. It is shown that the formation of an attachment relationship can be challenging for a prematurely born baby. (Føreland et al. 2022, 1-5; O'Brien et al. 2013, 6.) The parental participation in the care of a premature baby is seen as crucial to developing parenting skills. When the parents are seen as a member of the care team of a premature baby and their opinions are taken into consideration, the care supports the whole family, not only the premature baby. (O'Brien et al. 2013, 6-7.)

The NICU nurses said that KUH NICU utilises a comprehensive package of written guidance material. They pointed out in the interviews that it is a good base for uniformed information, although the material should be updated. There is a large quantity of separate printed sheets and not all the material is used. The interviewed nurses presented their experiences on how parents have questions and worries about the prognosis, medication and feeding issues concerning their prematurely born baby. It was found that the guidance is personalised according to the needs of the certain family and the situation. Continuity of guidance was seen as important, even if the nurse on duty changes during the hospitalisation time. The interviewed nurses' view of families' experiences of guiding was consistent: the parents are satisfied with the guidance overall. Sometimes the parents have given feedback about inconsistent guidance.

By enabling the parental presence, parents in KUH NICU are told to be the experts in knowing their own baby, and as KUH NICU offers single family rooms for all inpatients, it supports the full-time parental presence. Both parents can stay with their baby during hospitalisation. The research shows that parents should be seen as the main source of the premature baby's strength and support. Parental independency in nursing tasks increases as the care path progresses and therefore, the meaning of a supportive environment cannot be too highlighted. (Banerjee et al. 2017, 8–9; Gehl et al. 2019, 59; Pettoello-Mantovani et al. 2009.) The research findings of this thesis supported this view. This view was supported in all nurse interviews.

Although single-family rooms are developed to support parents, settling to the family room is not always easy. The interviewed nurses expressed their views that the environment is usually hectic after a premature baby is transferred to the NICU. They said that especially the first weeks after the delivery are the most restless time. The nurses said that parents have sometimes found it difficult to settle there as a health care professional just walks into the room whenever the baby needs it. It was discussed in several interviews that the care of a premature baby depends on time, parents typically can be caught up in the hospital’s routines for unnecessarily long time. As the baby grows, there is a need to support the observed needs of the baby instead of merely watching the clock and performing scheduled care.

An environment that supports family integrated care does not only mean facilities but also factors related to psychological support and coping (O’Brien et al. 2013, 6-7). The material produced from the interviews supported this view as parents are taken along to the multiprofessional team. The nurses said that parents are encouraged to participate in the care of their premature baby and express their opinions and wishes. This was seen as part of everyday activities. It was noted that sometimes hurry can influence the parent’s willingness to ask care related questions, even if it could have been answered easily. It was the view of the interviewed nurses, that empowering the parents to also be advocates for their baby is one of the most valuable ways for a NICU nurse to support parents. The interviewed nurses described this process can be long when it comes to premature babies but felt to be a fruitful path in the end. The parent interview supported this view.

In the interviews the nurses described the protocol of named nurse system. Every prematurely born baby should have a small group of named nurses who are on duty taking care of the premature baby whenever possible (see Appendices 5-7). The nurses described this role as significant for the parents. It helped them to cope with the stressful situation. Within the interviews, it was repeated several times how important the named nurse was to parents. They had a special connection with the named nurses. The interviews also revealed the fact that not every family has a named nurse, even though this should be the case according to protocol. Also, the named nurse is rarely able to discharge the premature baby because their expertise was needed to care for another sick or premature baby.

A supportive environment in KUH NICU also offers the protocol of weekly discussions (see Appendices 5-7). The nurses said these discussions should be planned and executed weekly according to the need of the parents. Also, reporting after the discussion was seen as important to share the information with health care professionals. Unfortunately, the nurses stated in the interviews that they are not implemented systematically due to time and resource constraints at the unit. The incomplete reporting of the insights was discussed, and nurses said they have experienced miscommunication. On the other hand, the nurses said that the neonatologist meet and talk with the parents daily with a doctor’s rounds. The parents can ask questions and their thoughts are heard.

Professionalism of NICU nurses was not the least important aspect to support parents. The nurses reflected on their own professionalism, and in several interviews, it was stated that professionalism gives nurses the sensitivity to face families genuinely. This gained experience gives a deeper understanding of things, and a skilled nurse can encourage parents even in the most challenging situations. The nurses highlighted the importance of an unhurried presence with families. This was seen as crucial. Even though the premature baby needs continuous attention, talking with the parents about everyday things inside the family room was seen as a significant link to the parents. Peer learning was also pointed out in the interviews, newer nurses could learn from a more experienced colleague. As parents are actively participating in the care, learning manual skills is more challenging for newer nurses.

8.3 The discharge plan in KUH NICU

Balasundaram et al. (2022, 108) have stated in their research that the quality of the discharge planning is a significant predicator of the parents’ ability to be transferred home safely with their premature baby. There is risk for readmission and parental anxiety if the discharge takes place without careful planning. (Balasundaram et al. 2022, 108.) Research also indicates that it is impossible to develop a discharge plan that would serve all families with unique needs. That is why the planning should be done to meet each families’ individual needs. The studies show the importance of family involvement into the discharge planning along the pare path in NICU. (Smith et al. 2022, 7.)

According to the interviews with KUH NICU nurses, the aim is that the discharge planning in KUH is visible for the families and the multiprofessional team working with the premature baby. The nurses said that the discharge planning protocol that KUH NICU utilises instructs to start discussion about discharge after the preliminary discharge date is set. The interviewed nurses agreed that the baby’s condition is influenced by the discharge planning. One example described in the interviews suggested that if the baby is unstable, there is no reason to discuss discharge yet. The nurse’s view was that sometimes the discussion is appropriate to take place later when the baby is more stable, and parents can participate more in the care of their premature baby. Research made by Smith et al. (2022, 7) states that even though there are uncertainties regarding the actual discharge date, an estimate of that would help parents prepare themselves for discharge.

Mostly, nurses recognised the discharge plan sheets, guiding parents to be more independent throughout the hospitalisation time and the printed home preparation guidance material to be the characteristics of the KUH NICU discharge plan program. Weekly discussions and named nurse systems were mentioned as operating models that effect on the discharge planning. Based on the nurse interviews, the recommendations by Smith et al. (2022, 8) related to discharge education partly come naturally as a part of every day in KUH NICU.

When referring to the recommendations by Smith et al. (2022, 8-9), family comprehension and the characteristics related to that seem almost automatic to the interviewed nurses, since in a unit with single-family rooms and parents present all the time the collaboration with the families is intense and constant. The question remains if the protocols are as visible to the families as they are to the NICU nurses. Smith et al. (2022, 9) propose tools like NICU roadmap, discharge planning folder and written discharge information available for the families. A roadmap should include discharge related goals, tasks and suggested preliminary timelines for families to achieve them. Smith et al. (2022, 9) also suggest the roadmap should include medical milestones for the baby, including unique developmental progression. (Smith et al. 2022, 9.) The discharge planning folder should include material and checklists to be used during the discharge planning process. Printed material should be clear and concise, and the aim should be to deeper the understanding. Only reviewed material should be used to meet health education standards. (Smith et al. 2022, 9.)

KUH NICU implements printed discharge forms related to guiding and to discharge (see Appendices 5-7). The interviewed nurses reported that some of the materials provide clear and consistent information, but some of the material is not in use systematically. It was stated in every interview that there are great differences in how and when the sheets are reviewed. It was agreed that the material needs to be updated and compiled into one cover instead of numerous separate forms and sheets. KUH NICU does not currently have a specific NICU roadmap that could be presented to the families. The checklists presented in Appendices 5 and 6 describe the care path the most comprehensively of the current available material. From these materials, the checklist in Appendix 5 was viewed by the nurses to be more helpful for the professionals rather than to the family. The list presented in Appendix 6 is rarely in use.

Even though the KUH NICU has created instructions and an operating model for the discharge planning, there is no clear operating model on the roles and responsibilities among health care professionals related to discharge planning in the unit. The reporting about discharge planning is partly utilised in the electronic patient information system, where it is not visible for the NICU families. In the interviews it became clear that the unit does double recording, some of the information is recorded in the electronic patient information system and some on paper forms, when they are in use. Smith et al. (2022, 9-10) state, that a comprehensive discharge care plan should be the foundation of the care path for every family in NICU. Important is to include a visible planning process and to make sure the family understand what is expected of them, during it. (Smith et al. 2022, 7, 9-10.)

8.4 Reliability of qualitative research

The basis of a reliable, trustworthy, and ethically approved research lies in following research guidelines for integrity (Juuti & Puusa 2020a, 168). The European responsible conduct of research and procedures key principles are generally defined. These principles are reliability, fairness, appreciation, and responsibility. Research integrity consists of methods that are considered during the research process. (TENK 2023, 12.) This thesis conforms to the principles mentioned above. In this thesis, reliability of the research was ensured with good planning and choosing proper, scientifically approved methodologies and data analysing methods for the research. Previous research and knowledge of the chosen topic were studied and gathered carefully, and their findings were considered when planning the thesis research. Appropriate acknowledgements were given with proper quotations to the publications.

According to the principles, all activity in this thesis was reported openly and impartially, without hiding anything. Good research practices also show appreciation to colleagues and the parties involved in the research, as well as ecosystems. The purpose, as well as the needs of this thesis was discussed with NICU managers, and the thesis authors visited NICU on several occasions during the research process and remained in contact with the NICU staff via e-mail to demonstrate the progress of the research. Researchers take responsibility of their entire research process. This responsibility also extends to publishing the research as well as to management, training, and guidance to the extent necessary. Good research practices are part of an organisation's science- and research communities quality systems. (TENK 2023, 11–14.)

A part of a good scientific research principles is to retrieve proper permits, consents, and ethical pre-assessment if necessary. The permits need to be retrieved before any data collection is done. (TENK 2023, 13.) For this thesis, a research permit, and later an extension to the original permit was applied from the client organisation, KUH (Appendix 1). The need of an ethical pre-assessment was discussed. An ethical pre-assessment is done before data collection, and it cannot be retrieved afterwards. A thesis author is always responsible of the ethical principles of their own work. (TENK 2019, 14.) Because of this, it was important to discuss and determine the nature of this thesis research properly at an early stage. Finnish National Board on Research Integrity, TENK, states, that an ethical pre-assessment should be requested, if the research participation process differs from knowledge-based consent principle, if the research interferes with physical immunity of the participants, the research is aimed at people under the age of 15 without a separate guardian consent or information, the research includes presenting subjects to exceptionally strong stimuli, the research may cause the participants exceptional amount of mental distress or, participating in the research can cause a security risk to the research participants or to the researcher. (TENK 2019, 16-17.) It was determined based on these recommendations, that this thesis does not need an additional ethical pre-assessment. The retrieved research permit states the purpose of the thesis in full, and it does not fulfil the criteria for pre-ethical evaluation.

When conducting a quality assessment of qualitative research, assessing the ethical needs to be done. Ethical principles are portrayed in a national guidance made by TENK (2019). The general ethical principles guiding all research work include honouring the self-determination of those individuals that are eligible to participate in the research. This right for self-determination includes the right to freedom of speech and a right to privacy. In addition, the research process must not cause any harm to the participants. (Puusa & Juuti 2020, 189; TENK 2019, 7.) In this thesis research process, special attention was paid to data protection issues and making sure voluntary participation. Since the thesis authors were already familiar with the environment of NICU and the characteristics of the unit by professional experience, it was easier to plan to ensure the before mentioned issues are taken into consideration. Though, it was crucial and challenging to ensure that no feeling of being pressured will be generated to the NICU families or to the NICU nurses. TENK highlights, that it is particularly important to ensure that participation is done voluntary, if the eligible participants have a relationship to the organisation based on working relationship or some other dependency. (TENK 2019, 8.)

To ensure the voluntary participation from NICU families, all eligible participants received a letter from either shift manager or family worker. The protocol was that the thesis authors informed the shift manager and the family workers of the nature of the thesis research and the target group and provided the letters. Since the shift manager and the family workers had the knowledge of eligible families automatically, they then provided the letters forward to the families. NICU nurses received the letter after agreeing via e-mail to participate to the research. The content of the letter is provided in Appendices 2-7. The identity of the research participants was kept secret, and participation in the research was not generally discussed. This was seen as important ethical aspect.

Following the ethical principles by TENK, the letter included privacy statement, and information of the purpose of the research. The eligible participants received information of what is to be expected of them if they agree to participate to the research, and how their personal data is handled. They also got information on how to cancel their participation to the research if they wanted to, and who to contact if they have any questions or if they'd want to receive additional information before consent. Knowledge-based consent is a key ethical principle of a study involving humans. (TENK 2019, 8.) This chosen method made it possible to not have to handle any personal data before receiving the actual agreement for the research and made sure no unnecessary personal data is handled by the thesis authors before receiving a written consent. It was also considered an ethically sustainable method as parents had the possibility not to participate in the research completely anonymously.

Research guidelines for integrity include making an agreement of ownership, storage, and processing, before collecting any material for the research (TENK 2023, 13). In the letter, it was told that the signed consent forms will form a personal data register, and the forms would be kept in a locked room until the thesis is published. Only the thesis authors had access to the forms, and the other thesis author was named to be the register keeper. The name of the register keeper was included in the privacy statement, and it was made known to all research participants. The register keeper is responsible for making sure the personal data is protected properly. The personal data needed from the participants included their name, e-mail address or phone number. (Henkilötietojen käsittely s.a.; TENK 2019, 11-12.) Responsibility of handling the personal data systematically, responsibly, and according to the laws applies to the whole life cycle of the research, and the methods used to ensure that need to be available to be checked afterwards by the organisation, if necessary. (TENK 2019, 11.) In addition to giving consent, the personal data collected was necessary to collect to contact the participants to arrange an interview time or inform them of possible changes in relation to the research process.

Since only one volunteer family wanted to participate in the research, it was discussed whether a personal contact from the thesis authors would have made a difference. Hirsjärvi & Hurme (2022, 86) point out, that above all, it is the researcher's responsibility to get the eligible participants to agree. Furthermore, they point out that some individuals have a natural habit to avoid new situations. But when the topic is explained to them more throughout, they might get excited. (Hirsjärvi & Hurme 2020, 86.) Since the thesis authors were unexperienced researchers, the recruiting process was challenging. Previous experience could have led to different results during the process. The opinion of Hirsjärvi & Hurme (2022, 86) is, that despite of the critic this approach has received, the researcher should be more active in persuasion. Their view is persuasion highlights the need of every participant individually, and it can make the participants see their uniqueness and importance better. (Hirsjärvi & Hurme 2020, 86). The thesis authors wanted to avoid pressuring the NICU families into consent. Personal contact from the thesis authors at that time was viewed as unethical, since the time close to discharge date from NICU can be emotional and stressful time. However, it was discussed that with personal contacts the thesis authors could have made sure every family is contacted in a similar way, and the thesis research purpose is explained more understandably.

According to Aaltio & Puusa (2020, 169) the ideal state of qualitative research is to separate the researcher's own views on the matter or phenomenon under research. The credibility of the research is increased by the fact that the researcher tries to identify their own subjectivity. Also, considering the values that are essentially related to the research progress and outcome should be identified by the researcher. Since the goal of scientific research and analysis is to produce reliable information, the viewpoints of the research subjects should be presented impartially. (Aaltio & Puusa 2020, 169.) In this thesis the interview material was processed and analysed impartially, even though both researchers had background information from their years of experience of working in NICU. Special attention was paid to the fact that the conclusions would not be influenced by one's own professional experience, but that they would be based only on issues raised in the research. Being able to rationalise the results and to visualise different working stages increase reliability and help to determine the truthfulness of the research results. In this thesis the visualisation of different working stages was demonstrated with multiple figures that were supported by theoretical framework and the chosen thesis methodology. There is no unequivocal guideline for assessing the reliability of qualitative research, but the chosen approach and methodology must be uniform throughout the process. (Puusa & Juuti 2020, 144; Tuomi & Sarajärvi 2018, 127, 163.)

Familiarising with the literature can be time consuming and when the knowledge of the chosen phenomena increases, the researchers can choose to change or modify the purpose of the work. (Puusa & Juuti 2020, 11.) The searched articles for this thesis were about premature babies, premature babies care in neonatal intensive care, family integrated care, parental guidance in NICU environment, and digital care paths. The reliability of the information retrieval was increased by seeking and using the expertise of the Savonia University of Applied Sciences library's informaticist. The use of multiple databases also increased reliability of the information retrieval. For the theoretical framework, appropriate references were used to respect the work of authors of the studies. The reliability was assessed throughout the thesis process, and the effort was to write openly about the chosen solutions.

Direct quotations were chosen not to be included in the text of this thesis as the interviews were done in Finnish. The thesis authors were worried the actual meaning could have changed during the interpretation from Finnish to English. Also, Puusa & Juuti (2020, 13) point out, that direct quotations themselves do not prove or verify anything. In addition, direct quotations can lead to a superficial analysis without proper interpretations of the research material. (Puusa & Juuti 2020, 13.) It is also advisable to take into consideration, that removing the names from the collected research data does not necessarily prevent the identification of the participants, and that publishing very specific data of people who know the targeted organisation activity well might lead to them being recognized. (TENK 2019, 11-12.) It was the main concern of the thesis authors that with only six participants handing out many direct quotations might result in accidental publication of recognizable individual phrases. During the content analysis, the data was translated to English in the classification phase (see Appendix 9). When the reduction was done to the original transcribed data, it was more natural to form an English lower class and furthermore upper and main classes without the fear or losing any important data.

8.5 Thesis methodology

The preparation of the thesis research was supported by a carefully designed research plan. Typically, it is better to form the research questions and the purpose of the research first before methodological choices. In this way the methodologies will not limit the research topic and it can be chosen more freely according to the pressing needs. (Puusa & Juuti 2020, 11.) In this thesis the topic was discussed first at KUH NICU. The theoretical framework was produced by information retrieval. It was done by search engines offered by the library of Savonia University, Finna. The information retrieval was performed from the database by searching research articles from year 2015 until this day.

After determining the thesis purpose, goals and research questions, service design methodology was chosen for this thesis as the aim was to start developing a novel service. The goal of gathering the views and knowledge of those with experience of the current care path and protocols in KUH NICU shaped the thesis into a qualitative research project. Service design and qualitative research complement one another, since with both approaches the goal is to understand the chosen research phenomena from the perspective of the individuals involved. Both approaches take interest in the significations, thoughts, and feelings the individuals give. This also led to the conclusion that conducting thematic interviews was a justified way to collect data for the thesis research. (Puusa & Juuti 2020, 9; Tuulaniemi 2011.) The UK Design Council’s double diamond model was found to be useful and informative model to visualise the service design process (see Figure 1; Design Council 2023).

The challenge with the double diamond model, as well as in qualitative research overall is, that a clear distinction cannot always be made between different phases. Typically, with the service design process it is necessary to go back to the previous step and reformulate it. A qualitative research process also recognises the same need, and the flexibility of the research setup usually ensures that the research can also move backwards during the process and the researchers can reform their original choices. Even when the research is done from a specifically chosen perspective and theoretical perspective, it should always be made possible to go back and refine the research tasks even further as needed. (Puusa & Juuti 2020, 75-76.) Long work experience among the chosen phenomena can also contribute to the difficulty of separation of the process phases, in which case customer understanding is already part of every day’s work. (De Goey et al. 2019, 724; Puusa & Juuti 2020, 11.) In this thesis process the original plan was reformulated on several occasions as the work progressed. Determining a sufficiently limited topic was challenging, as both thesis authors are former KUH NICU professionals, and they have a lot of know-how from FICare. The challenges with the topic partly led to the prolongation of the thesis process. However, the reformulations were found necessary to delimit the research properly, and to reach the set goals with good quality research (see Figures 2-3).

Puusa & Juuti (2020, 11) remind researchers that the goal of a sole qualitative research should not be focused on solving all problems related to the chosen topic. Furthermore, they emphasise that in qualitative research "less is more", and it is more appropriate to aim for an in-depth knowledge rather than a superficial, general level analysis of too many themes. Even with proper delimitation, qualitative research data is usually rich with information and can include unexpected themes or interesting facts outside of the original scope of the research. (Puusa & Juuti 2020, 11, 141.) As it can be seen from the Appendix 4, originally the thesis research had four separate themes prepared for the thematical interviews. After all the interviews were finalised, the amount of data was so extensive that it was seen beneficial for the research to delimit the data for content analysis to answer the thesis research questions better. The dialogue about a future digital path with the NICU nurses was rich, interesting, and full of innovative ideas for the future, however they were outside of the scope of the thesis purpose, that was to study the current care protocols in KUH NICU.

The content analysis was done carefully and following good scientific practise. The analyse is a multiphase process, where interpretations are made constantly. Carefully executed content analysis should help in organising the research data into a clear format without losing essential information. Reduction is a necessary phase, and its purpose is above all increase the informational value. It is important to understand despite qualitative research material is usually extremely rich, without reduction, clustering and classifying, the data as it is can be shattered. (Puusa & Juuti 2020, 144.)

Transcribing the interview recording was a laborious work phase. In their book, Hirsjärvi & Hurme (2022) refer to Alastalo (1997, 7) pointing out that solely transcribing an interview requires already six to ten hours of time even from a fast typewriter. Furthermore, Alastalo (1997, 7) reminds that every additional code prolongs the working time needed. Hirsjärvi & Hurme (2022, 144-145) emphasise choosing the transcribing precision according to the needs and goals of the research itself and recommend refraining from exact transcription of the material if it is not necessary. (Hirsjärvi & Hurme 2022, 144-145.)

Analysing interview material of this magnitude was a new, time-consuming challenge for both thesis authors. To not lose any valuable information a decision about literal transcription was made. In retrospect, time could have been saved when considering the thesis research tasks and the thesis goal. Some of the interview material was unrelated to the exact research questions and therefore was not a part of the content analysis itself. Also, some of the interviews were executed remotely via Teams. This type of interview may suit better to a more structured interview than to a qualitative interview. This is, because a remote interview makes it impossible for the researcher to catch hints like facial expressions or reasons for pauses during the dialogue. (Hirsjärvi & Hurme 2022, 65.) This was a known risk, however in order to make the interview possible for as many participants as possible, the thesis authors chose to provide the participants with the possibility of a remote interview.

The thesis process was fascinating even though challenging at times. The process turned out to be longer than expected. As both thesis authors were working at KUH NICU at the time the idea for thesis was introduced, it was a particularly significant topic for both. A working life-oriented perspective was seen as in important approach. Different working methods were discussed and a coherent way to produce the research was found. Choosing service design to be the main methodology of this thesis taught how a design process works. The thesis authors' view is that service design methodology is a proper and effective way to start developing a digital service. Notable is, how the design thinking of the thesis authors evolved during the process, as an understanding was reached of how labouring even the first part of the double diamond model can be. Visualising the thesis process with the help of the double diamond figure (see Figures 2-3) helped to understand the characteristics of every phase. It is the view of the thesis authors that using the double diamond visualisation can help maintain systematicity of the design process, even if the further part of the process is executed by different authors.

This thesis was produced by two authors. The content gathered for the thesis was extensive, as was the thesis project itself, therefore working as a pair was considered to be a strength. The thesis authors believe sharing thoughts and discussing with a partner in qualitative research effects on the result positively. Also, having a partner for a thesis process teaches about teamwork, and scheduling. The greatest challenge with this thesis was the delays experienced during the process, some of which were unexpected. As the thesis authors were not full-time student during the thesis process, sometimes it was found challenging to find time together. Although, working with a partner was helpful when the ideas did not flow, or one of the thesis authors had a busier schedule. Sharing the work during those times ensured moving forward with the process despite the challenges.

The thesis authors used Microsoft Teams as a platform to share all thesis related documents. Up-to-date version of the thesis was always available and accessible for both thesis authors, and enabled working simultaneously. Teams conference calls were organised to share thoughts and, to perform supervisions with teachers. Usually, the workload was divided so that the thesis authors focused working on different parts of the thesis. Then, the completed parts were presented to one another and discussed, so both thesis authors had a comprehensive understanding of the process and the theoretical framework related to it. Composing a thesis as a team should always be an option but not mandatory. It was particularly important in this thesis project when carrying out the interviews, as it was a new challenge for both thesis authors.

8.6 Future research opportunities

Many times, research objectives are described to be unknown in advance, portraying a subject that has never been studied before. However, the goal is not always to find a theme that has not been studied, specially not in a qualitative study. Room needs to be given to the for the material collected, and ultimately the goal is to with open minded and flexibly start looking for new perspectives from the chosen phenomena. Rather than answering to a pre-set strict hypothesis, the aim is to provide new insights to develop the phenomena further. (Puusa & Juuti 2020, 75-76.) As the lack of systematicity in guidance came up in all the interviews, the future digital care path can offer reliable and accessible source of information to all NICU families. It will not replace the face-to-face given guidance, but it could guarantee the basis for the guidance. Also, the lack of resources was discussed in the interviews. The fact, that not all families receive the prenatal information due to hurry at NICU, could be solved by implementing a digital care path. The families would be enabled to access information concerning premature baby and their care after delivery regardless of time and conditions.

Both family integrated care principles and service design methodology recognise the importance of user-centred approach in providing care and services. In service design, the collaboration with future service users, and their input into service planning is in key role. In FICare, collaboration with the parents and their participation in care planning is in key role. (Design Council 2023; O'Brien et. al. 2013.) In the future, integrating FICare principles and service design methodologies to a qualitative research approach can result in more comprehensive, patient-centred care models, where the needs of the patients or customers are determined through participation and collaboration.

The double diamond model applies service design methods like focus groups, brainstorming, customer journey mapping, service blueprinting and testing in different parts of the model and process, which are all possible to use in collaboration with the stakeholders. The methods are meant to be helpful in recognising perceptions, thoughts, and innovations of the future service users better, as well as to understand the service entity better. (Design Council 2023.) Using service design methodology and particularly the double diamond model in developing family integrated care in the future could offer a systematic research planning and executing method. This could guarantee comparability of research results on a larger scale. The consistent positive outcomes reported in the studies encourage further examination of the benefits of eHealth solutions in NICU, however Dol et al. (2017, 2996) consistently point out the need for further research in their systematic review. Currently, small sample sizes in studies limit generalisation and many times prevent researchers from doing meaningful statistical analysis. This was also a challenge in this thesis. Also, there is a significant variation in methodological choices and the heterogeneity of the studies prevent researchers from making any certain conclusions or providing meta-analyses. (Dol et al. 2017, 2993–2996; Richardson et al. 2019.)

The content analysis and the results of this thesis portray the current state of family integrated care in KUH NICU. In addition, during the interviews with the nurses and with the NICU parent it was also discussed in multiple occasions that it would be a more useful and modern way to digitalise the care path of a prematurely born baby in KUH NICU. Digital care path is meant to offer accessible and trustworthy information for the user regardless of time and place (Kaihlaniemi et al. 2023, 4781), and the interviewees felt this solution could be beneficial in KUH NICU also. KUH NICU can utilise the results of this thesis when designing the future digital care path. There is a demand for digital care paths and the thesis meets this purpose. This thesis is therefore timely and necessary, but future research and development is needed. It is also notable to mention, that internet-based health content has been reported to be variable in quality and credibility. Richardson et al. (2019) evaluated applications downloadable from Google Play and Apple store. Their evaluation showed less than half of the applications were acceptable to be used as educational material for parents.

Also, even though the apps were being updated, it is not always clear whether the content itself updated or only technical aspects like fixing delays. Because of this, it is important to promote developmental work related to digital care paths with systematic, reliable research methods in the future.

The main challenge is to get NICU parents to participate more actively in the future research and developmental projects. As it is typical for service design methodology to also allow going back to previous stages of the double diamond model, for the next step of the digital care path development it would be crucial to assess again, how to achieve more systematic collaboration with the NICU parents and continue defining the needs of the parents more systematically. The six NICU nurse interviews provided consistent data of the current care practices in KUH NICU, however the results should be more specifically validated from parental perspective. Whether the saturation of the material was achieved may need to be further studied. In order for the saturation of the material being successful, new interviewees will not provide any new essential information, that would have not already come up in the previous interviews. It is up to the researcher to be able to decide when the interviews have given enough information for theoretically significant results. (Hirsjärvi & Hurme 2022, 60.)

The task of creating the digital care path for a prematurely born baby in KUH NICU using the service design model will be a goal for future projects. KUH NICU has great operation models and guidelines developed. However, not all seem to be implemented according to the protocol. Based on this thesis results, a recommendation can be made for further research of how a digital solution could help resolve the challenges related to KUH NICU family integrated care protocols brought up by NICU nurses. The challenges like lack of resources in an often busy NICU environment and lack of systematicity in parental guidance could be resolved with a uniform, comprehensive digital care path.

The printed discharge plan program also has potential to be transformed into a digital form as a part of the future digital care path solution. However, further assessment and validation need to be concluded first about the usability of the current sheets, and reasons why the sheets are currently not in use need to be studied more. Possibly, the sheets need to be updated, compounded, or renewed to meet the needs of the families better. For example, discharge planning guidelines and recommendations by Smith et al. (2022) offer material about discharge education, planning tools, planning team, planning process and family and home needs assessment content in form of tables with supporting references. Guidelines like Smith et al. (2022) could help KUH NICU to also modify and develop the current discharge planning protocol into a more comprehensive part of the family integrated care and be a helpful guideline in creating a future digital care path. Research has shown the success of electronic guidance material among NICU parents. Balasundaram et al. (2022, 110-114) have developed one version for discharge education for NICU parents. They compiled all educative material into digital format to improve the outcome of the discharge process. Also, research shows that parents have forgotten paper forms concerning discharge. They brought up that it would be convenient if the material was in a digital format. (Dol et al. 2017, 2996.)

Ultimately, it is the goal of the authors of this thesis project that the findings of this project will be further studied and developed into a ready digital platform to use in the family integrated NICU.

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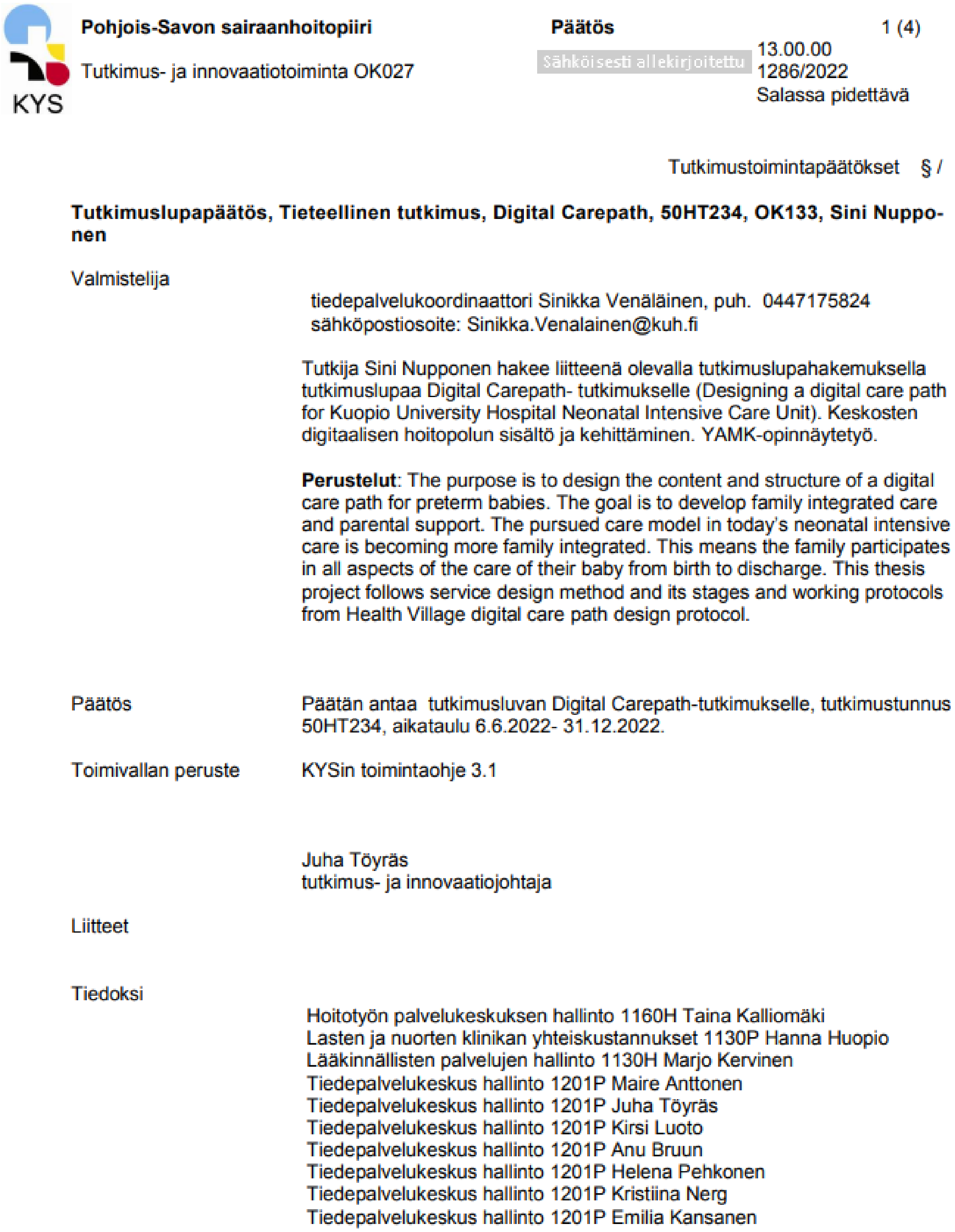
APPENDIX 1: RESEARCH PERMITS



Pohjois-Savon sairaanhoitopiiri
Tutkimus- ja innovaatiotoiminta OK027

Päätös 1 (4)
Sähköisesti allekirjoitettu
13.00.00
1286/2022
Salassa pidettävä

Tutkimustoimintapäätökset § /

Tutkimuslupapäätös, Tieteellinen tutkimus, Digital Carepath, 50HT234, OK133, Sini Nupponen

Valmistelija

tiedepalvelukoordinaattori Sinikka Venäläinen, puh. 0447175824
sähköpostiosoite: Sinikka.Venalainen@kuh.fi

Tutkija Sini Nupponen hakee liitteenä olevalla tutkimuslupahakemuksella tutkimuslupaa Digital Carepath- tutkimukselle (Designing a digital care path for Kuopio University Hospital Neonatal Intensive Care Unit). Keskosten digitaalisen hoitopolun sisältö ja kehittäminen. YAMK-opinnäytetyö.

Perustelut: The purpose is to design the content and structure of a digital care path for preterm babies. The goal is to develop family integrated care and parental support. The pursued care model in today's neonatal intensive care is becoming more family integrated. This means the family participates in all aspects of the care of their baby from birth to discharge. This thesis project follows service design method and its stages and working protocols from Health Village digital care path design protocol.

Päätös

Päätän antaa tutkimusluvan Digital Carepath-tutkimukselle, tutkimustunnus 50HT234, aikataulu 6.6.2022- 31.12.2022.

Toimivallan peruste

KYSin toimintaohje 3.1

Juha Töyräs
tutkimus- ja innovaatiojohtaja

Liitteet

Tiedoksi

Hoitotyön palvelukeskuksen hallinto 1160H Taina Kalliomäki
Lasten ja nuorten klinikan yhteiskustannukset 1130P Hanna Huopio
Lääkinnällisten palvelujen hallinto 1130H Marjo Kervinen
Tiedepalvelukeskus hallinto 1201P Maire Anttonen
Tiedepalvelukeskus hallinto 1201P Juha Töyräs
Tiedepalvelukeskus hallinto 1201P Kirsi Luoto
Tiedepalvelukeskus hallinto 1201P Anu Bruun
Tiedepalvelukeskus hallinto 1201P Helena Pehkonen
Tiedepalvelukeskus hallinto 1201P Kristiina Nerg
Tiedepalvelukeskus hallinto 1201P Emilia Kansanen

Pohjois-Savon hyvinvointialue

Hallintopäätös 1 (2)

Strategia- ja kehittäminen 3/13.00/2023

16.01.2023 Salainen

§ 1/2023

Tutkimusluvan muutospäätös Digital Carepath 50HT234, PY4206, Nupponen Sini

Valmistelija(t) Tiedepalvelukoordinaattori Nerg Kristiina, puh. 044 717 4950, sähköpostiosoite: kristiina.nerg@pshyvinvointialue.fi

Tutkija Sini Nupponen ja Niina Huhtamäki hakevat jatkoaikaa tutkimuksensa Digital Carepath suorittamiseksi 30.6.2023 saakka hakemuksen liitteiden mukaisesti. Hakemus liittyy 8.9.2022 tehtyyn tutkimuslupapäätökseen (asianro 1286/2022/D360).

Tutkimuksen tavoitteet ja asetelma: The purpose is designing content and structure of a digital care path (DCP) for preterm babies. The goal is to develop family integrated care and parental support together with the regisrered nurses. Family integrated care means the family participates in all aspects of the care of their baby from birth to discharge. This thesis project follows service design method and its stages.

This thesis project will use thematic interviews as a data collection method and qualitative content analysis for exploiting the results. Eligible for interviews are nurses with minimum of 2 years working experience in KUH NICU. The goal is to define how to benefit from current discharge plan in use at KUH NICU in DCP development and find out what the nurses feel are the most important themes to address in DCP in order to increase family integration.

Päätös Myönnän luvan jatkaa Digital Carepath 50HT234 -tutkimusta päätöspäivämäärästä 30.6.2023 saakka.

Toimivallan peruste Strategia- ja kehittämisjohtajan päätös, § 11/2023

Salassapitoperuste JulkL 24.1 § 21 (opinnäytetyön tai tieteellisentutkimuksen suunnitelma tms)

Aluehallitus

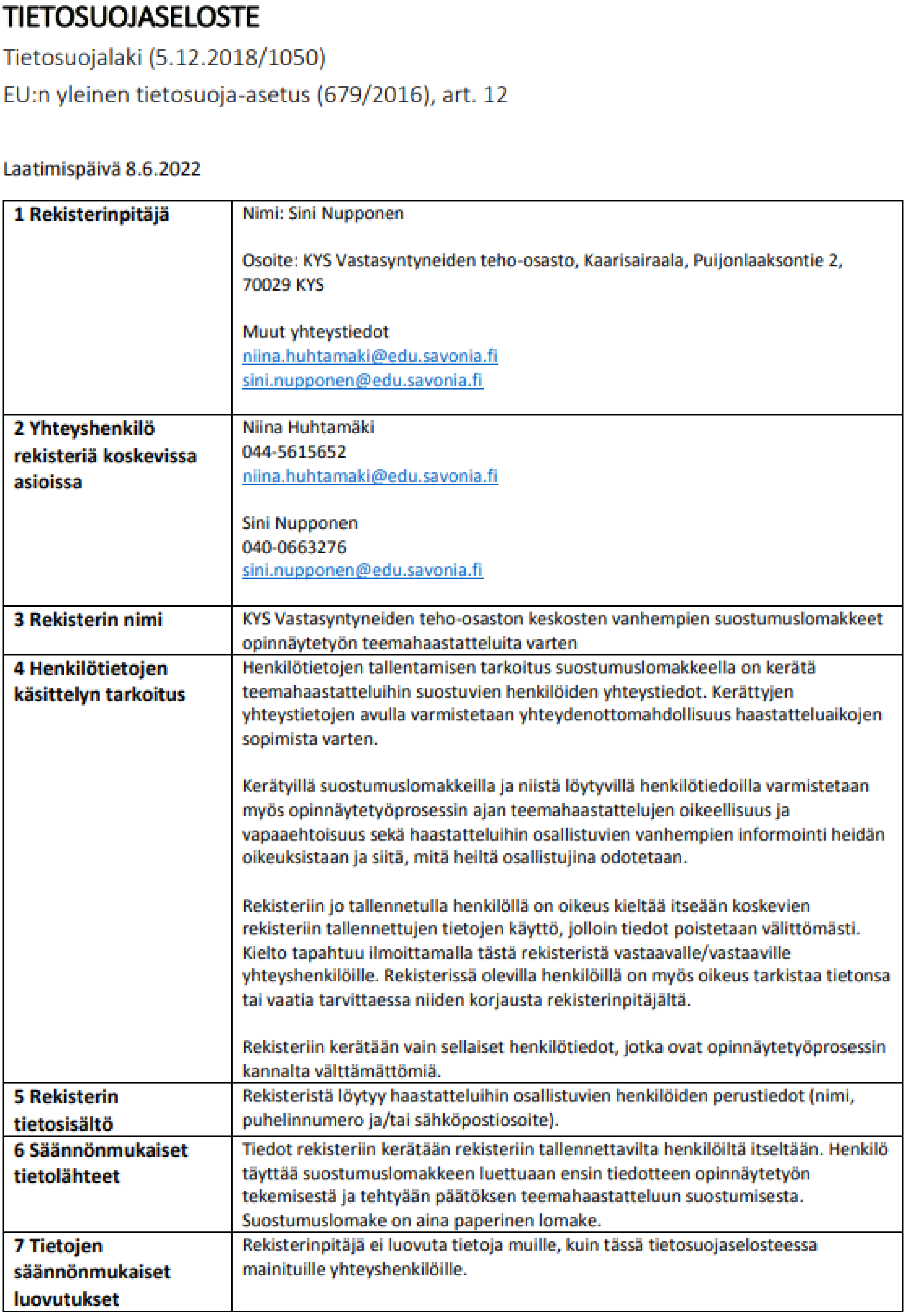
Juha Töyräs
tutkimus- ja innovaatiojohtaja

Tämä asiakirja on sähköisesti allekirjoitettu Pohjois-Savon hyvinvointialueen asianhallintajärjestelmässä.

Liitteet	Oikaisuvaatimusohje aluehallitus PSHVA Liite 1 Allekirjoitettu tutkimuslupahakemus Ei-julkinen asiakirja Ei-julkinen asiakirja Ei-julkinen asiakirja Ei-julkinen asiakirja Ei-julkinen asiakirja

Jakelu

APPENDIX 2: PRIVACY STATEMENTS



TIETOSUOJASELOSTE

Tietosuojalaki (5.12.2018/1050)
EU:n yleinen tietosuoja-asetus (679/2016), art. 12

Laatimispäivä 8.6.2022

1 Rekisterinpitäjä	Nimi: Sini Nupponen Osoite: KYS Vastasyntyneiden teho-osasto, Kaarisairaala, Puijonlaaksontie 2, 70029 KYS Muut yhteystiedot niina.huhtamaki@edu.savonia.fi sini.nupponen@edu.savonia.fi
2 Yhteyshenkilö rekisteriä koskevissa asioissa	Niina Huhtamäki 044-5615652 niina.huhtamaki@edu.savonia.fi Sini Nupponen 040-0663276 sini.nupponen@edu.savonia.fi
3 Rekisterin nimi	KYS Vastasyntyneiden teho-osaston keskosten vanhempien suostumuslomakkeet opinnäytetyön teemahaastatteluita varten
4 Henkilötietojen käsittelyn tarkoitus	Henkilötietojen tallentamisen tarkoitus suostumuslomakkeella on kerätä teemahaastatteluihin suostuvien henkilöiden yhteystiedot. Kerättyjen yhteystietojen avulla varmistetaan yhteydenottomahdollisuus haastatteluaikojen sopimista varten. Kerätyillä suostumuslomakkeilla ja niistä löytyvillä henkilötiedoilla varmistetaan myös opinnäytetyöprosessin ajan teemahaastattelujen oikeellisuus ja vapaaehtoisuus sekä haastatteluihin osallistuvien vanhempien informointi heidän oikeuksistaan ja siitä, mitä heiltä osallistujina odotetaan. Rekisteriin jo tallennetulla henkilöllä on oikeus kieltää itseään koskevien rekisteriin tallennettujen tietojen käyttö, jolloin tiedot poistetaan välittömästi. Kielto tapahtuu ilmoittamalla tästä rekisteristä vastaavalle/vastaaville yhteyshenkilöille. Rekisterissä olevilla henkilöillä on myös oikeus tarkistaa tietonsa tai vaatia tarvittaessa niiden korjausta rekisterinpitäjältä. Rekisteriin kerätään vain sellaiset henkilötiedot, jotka ovat opinnäytetyöprosessin kannalta välttämättömiä.
5 Rekisterin tietosisältö	Rekisteristä löytyy haastatteluihin osallistuvien henkilöiden perustiedot (nimi, puhelinnumero ja/tai sähköpostiosoite).
6 Säännönmukaiset tietolähteet	Tiedot rekisteriin kerätään rekisteriin tallennettavilta henkilöiltä itseltään. Henkilö täyttää suostumuslomakkeen luettuaan ensin tiedotteen opinnäytetyön tekemisestä ja tehtyään päätöksen teemahaastatteluun suostumisesta. Suostumuslomake on aina paperinen lomake.
7 Tietojen säännönmukaiset luovutukset	Rekisterinpitäjä ei luovuta tietoja muille, kuin tässä tietosuojaselosteessa mainituille yhteyshenkilöille.

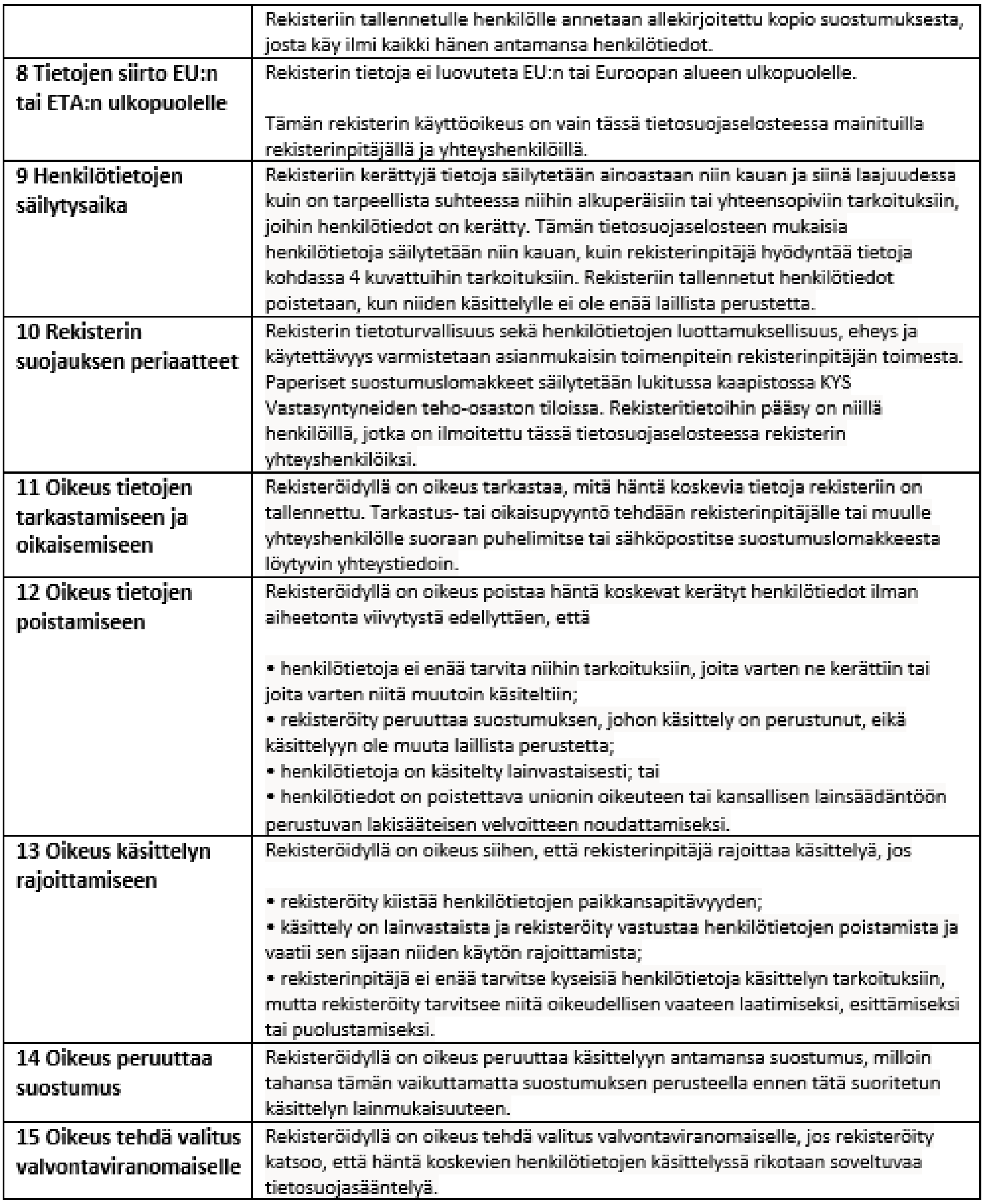
	Rekisteriin tallennetulle henkilölle annetaan allekirjoitettu kopio suostumuksesta, josta käy ilmi kaikki hänen antamansa henkilötiedot.
8 Tietojen siirto EU:n tai ETA:n ulkopuolelle	Rekisterin tietoja ei luovuteta EU:n tai Euroopan alueen ulkopuolelle. Tämän rekisterin käyttöoikeus on vain tässä tietosuojaselosteessa mainituilla rekisterinpitäjällä ja yhteyshenkilöillä.
9 Henkilötietojen säilytysaika	Rekisteriin kerättyjä tietoja säilytetään ainoastaan niin kauan ja siinä laajuudessa kuin on tarpeellista suhteessa niihin alkuperäisiin tai yhteensopiviin tarkoituksiin, joihin henkilötiedot on kerätty. Tämän tietosuojaselosteen mukaisia henkilötietoja säilytetään niin kauan, kuin rekisterinpitäjä hyödyntää tietoja kohdassa 4 kuvattuihin tarkoituksiin. Rekisteriin tallennetut henkilötiedot poistetaan, kun niiden käsittelylle ei ole enää laillista perustetta.
10 Rekisterin suojauksen periaatteet	Rekisterin tietoturvallisuus sekä henkilötietojen luottamuksellisuus, eheys ja käytettävyys varmistetaan asianmukaisin toimenpitein rekisterinpitäjän toimesta. Paperiset suostumuslomakkeet säilytetään lukitussa kaapistossa KYS Vastasyntyneiden teho-osaston tiloissa. Rekisteritietoihin pääsy on niillä henkilöillä, jotka on ilmoitettu tässä tietosuojaselosteessa rekisterin yhteyshenkilöiksi.
11 Oikeus tietojen tarkastamiseen ja oikaisemiseen	Rekisteröidyllä on oikeus tarkastaa, mitä häntä koskevia tietoja rekisteriin on tallennettu. Tarkastus- tai oikaisupyyntö tehdään rekisterinpitäjälle tai muulle yhteyshenkilölle suoraan puhelimitse tai sähköpostitse suostumuslomakkeesta löytyvin yhteystiedoin.
12 Oikeus tietojen poistamiseen	Rekisteröidyllä on oikeus poistaa häntä koskevat kerätyt henkilötiedot ilman aiheetonta viivytystä edellyttäen, että • henkilötietoja ei enää tarvita niihin tarkoituksiin, joita varten ne kerättiin tai joita varten niitä muutoin käsiteltiin; • rekisteröity peruuttaa suostumuksen, johon käsittely on perustunut, eikä käsittelyyn ole muuta laillista perustetta; • henkilötietoja on käsitelty lainvastaisesti; tai • henkilötiedot on poistettava unionin oikeuteen tai kansallisen lainsäädäntöön perustuvan lakisääteisen velvoitteen noudattamiseksi.
13 Oikeus käsittelyn rajoittamiseen	Rekisteröidyllä on oikeus siihen, että rekisterinpitäjä rajoittaa käsittelyä, jos • rekisteröity kiistää henkilötietojen paikkansapitävyyden; • käsittely on lainvastaista ja rekisteröity vastustaa henkilötietojen poistamista ja vaatii sen sijaan niiden käytön rajoittamista; • rekisterinpitäjä ei enää tarvitse kyseisiä henkilötietoja käsittelyn tarkoituksiin, mutta rekisteröity tarvitsee niitä oikeudellisen vaateen laatimiseksi, esittämiseksi tai puolustamiseksi.
14 Oikeus peruuttaa suostumus	Rekisteröidyllä on oikeus peruuttaa käsittelyyn antamansa suostumus, milloin tahansa tämän vaikuttamatta suostumuksen perusteella ennen tätä suoritetun käsittelyn lainmukaisuuteen.
15 Oikeus tehdä valitus valvontaviranomaiselle	Rekisteröidyllä on oikeus tehdä valitus valvontaviranomaiselle, jos rekisteröity katsoo, että häntä koskevien henkilötietojen käsittelyssä rikotaan soveltuvaa tietosuojasääntelyä.

TIETOSUOJASELOSTE

Tietosuojalaki (5.12.2018/1050)
EU:n yleinen tietosuoja-asetus (679/2016), art. 12

Laatimispäivä 1.12.2022

1 Rekisterinpitäjä	Nimi: Sini Nupponen Osoite: KYS Vastasyntyneiden teho-osasto, Kaarisairaala, Puijonlaaksontie 2, 70029 KYS Muut yhteystiedot niina.huhtamaki@edu.savonia.fi sini.nupponen@edu.savonia.fi
2 Yhteyshenkilö rekisteriä koskevissa asioissa	Niina Huhtamäki 044-5615652 niina.huhtamaki@edu.savonia.fi Sini Nupponen 040-0663276 sini.nupponen@edu.savonia.fi
3 Rekisterin nimi	KYS Vastasyntyneiden teho-osaston sairaanhoitajien suostumuslomakkeet opinnäytetyön teemahaastatteluita varten
4 Henkilötietojen käsittelyn tarkoitus	Henkilötietojen tallentamisen tarkoitus suostumuslomakkeella on kerätä teemahaastatteluihin suostuvien henkilöiden yhteystiedot. Kerättyjen yhteystietojen avulla varmistetaan yhteydenottomahdollisuus haastatteluaikojen sopimista varten. Kerätyillä suostumuslomakkeilla ja niistä löytyvillä henkilötiedoilla varmistetaan myös opinnäytetyöprosessin ajan teemahaastattelujen oikeellisuus ja vapaaehtoisuus sekä haastatteluihin osallistuvien vanhempien informointi heidän oikeuksistaan ja siitä, mitä heiltä osallistujina odotetaan. Rekisteriin jo tallennetulla henkilöllä on oikeus kieltää itseään koskevien rekisteriin tallennettujen tietojen käyttö, jolloin tiedot poistetaan välittömästi. Kielto tapahtuu ilmoittamalla tästä rekisteristä vastaavalle/vastaaville yhteyshenkilöille. Rekisterissä olevilla henkilöillä on myös oikeus tarkistaa tietonsa tai vaatia tarvittaessa niiden korjausta rekisterinpitäjältä. Rekisteriin kerätään vain sellaiset henkilötiedot, jotka ovat opinnäytetyöprosessin kannalta välttämättömiä.
5 Rekisterin tietosisältö	Rekisteristä löytyy haastatteluihin osallistuvien henkilöiden perustiedot (nimi, puhelinnumero ja/tai sähköpostiosoite).
6 Säännönmukaiset tietolähteet	Tiedot rekisteriin kerätään rekisteriin tallennettavilta henkilöiltä itseltään. Henkilö täyttää suostumuslomakkeen luettuaan ensin tiedotteen opinnäytetyön tekemisestä ja tehtyään päätöksen teemahaastatteluun suostumisesta. Suostumuslomake on aina paperinen lomake.
7 Tietojen säännönmukaiset luovutukset	Rekisterinpitäjä ei luovuta tietoja muille, kuin tässä tietosuojaselosteessa mainituille yhteyshenkilöille.



	Rekisteriin tallennetulle henkilölle annetaan allekirjoitettu kopio suostumuksesta, josta käy ilmi kaikki hänen antamansa henkilötiedot.
8 Tietojen siirto EU:n tai ETA:n ulkopuolelle	Rekisterin tietoja ei luovuteta EU:n tai Euroopan alueen ulkopuolelle. Tämän rekisterin käyttöoikeus on vain tässä tietosuojaselosteessa mainituilla rekisterinpitäjällä ja yhteyshenkilöillä.
9 Henkilötietojen säilytysaika	Rekisteriin kerättyjä tietoja säilytetään ainoastaan niin kauan ja siinä laajuudessa kuin on tarpeellista suhteessa niihin alkuperäisiin tai yhteensopiviin tarkoituksiin, joihin henkilötiedot on kerätty. Tämän tietosuojaselosteen mukaisia henkilötietoja säilytetään niin kauan, kuin rekisterinpitäjä hyödyntää tietoja kohdassa 4 kuvattuihin tarkoituksiin. Rekisteriin tallennetut henkilötiedot poistetaan, kun niiden käsittelylle ei ole enää laillista perustetta.
10 Rekisterin suojauksen periaatteet	Rekisterin tietoturvallisuus sekä henkilötietojen luottamuksellisuus, eheys ja käytettävyys varmistetaan asianmukaisin toimenpitein rekisterinpitäjän toimesta. Paperiset suostumuslomakkeet säilytetään lukitussa kaapistossa KYS Vastasyntyneiden teho-osaston tiloissa. Rekisteritietoihin pääsy on niillä henkilöillä, jotka on ilmoitettu tässä tietosuojaselosteessa rekisterin yhteyshenkilöiksi.
11 Oikeus tietojen tarkastamiseen ja oikaisemiseen	Rekisteröidyllä on oikeus tarkastaa, mitä häntä koskevia tietoja rekisteriin on tallennettu. Tarkastus- tai oikaisupyyntö tehdään rekisterinpitäjälle tai muulle yhteyshenkilölle suoraan puhelimitse tai sähköpostitse suostumuslomakkeesta löytyvin yhteystiedoin.
12 Oikeus tietojen poistamiseen	Rekisteröidyllä on oikeus poistaa häntä koskevat kerätyt henkilötiedot ilman aiheetonta viivytystä edellyttäen, että • henkilötietoja ei enää tarvita niihin tarkoituksiin, joita varten ne kerättiin tai joita varten niitä muutoin käsiteltiin; • rekisteröity peruuttaa suostumuksen, johon käsittely on perustunut, eikä käsittelyyn ole muuta laillista perustetta; • henkilötietoja on käsitelty lainvastaisesti; tai • henkilötiedot on poistettava unionin oikeuteen tai kansallisen lainsäädäntöön perustuvan lakisääteisen velvoitteen noudattamiseksi.
13 Oikeus käsittelyn rajoittamiseen	Rekisteröidyllä on oikeus siihen, että rekisterinpitäjä rajoittaa käsittelyä, jos • rekisteröity kiistää henkilötietojen paikkansapitävyyden; • käsittely on lainvastaista ja rekisteröity vastustaa henkilötietojen poistamista ja vaatii sen sijaan niiden käytön rajoittamista; • rekisterinpitäjä ei enää tarvitse kyseisiä henkilötietoja käsittelyn tarkoituksiin, mutta rekisteröity tarvitsee niitä oikeudellisen vaateen laatimiseksi, esittämiseksi tai puolustamiseksi.
14 Oikeus peruuttaa suostumus	Rekisteröidyllä on oikeus peruuttaa käsittelyyn antamansa suostumus, milloin tahansa tämän vaikuttamatta suostumuksen perusteella ennen tätä suoritetun käsittelyn lainmukaisuuteen.
15 Oikeus tehdä valitus valvontaviranomaiselle	Rekisteröidyllä on oikeus tehdä valitus valvontaviranomaiselle, jos rekisteröity katsoo, että häntä koskevien henkilötietojen käsittelyssä rikotaan soveltuvaa tietosuojasääntelyä.

APPENDIX 3: COVERING LETTERS

TIEDOTE OPINNÄYTETYÖSTÄ:

DIGIHOITOPOLUN KEHITTÄMINEN KYSIN VASTASYNTYNEIDEN TEHO-OSASTOLLA

Teitä pyydetään mukaan opinnäytetyöhön, joka keskittyy digihoitopolun kehittämiseen KYSin Vastasyntyneiden teho-osastolla. Olemme arvioineet, että soveltuisitte opinnäytetyöhön, sillä lapsenne on syntynyt keskosena ennen raskausviikkoa 34 KYSissä ja ollut hoidossa KYSin Vastasyntyneiden teho-osastolla. Tämä tiedote kuvaa opinnäytetyön tarkoitusta ja toteutusta sekä Teidän mahdollista osuuttanne siinä. Tämä tiedote annetaan luettavaksi kaikille perheille, joiden on arvioitu soveltuvan opinnäytetyöhön. Tämän tiedotteen antaminen Teille ei ole edellyttänyt henkilötietojen keräämistä.

Osallistuminen opinnäytetyöhön on vapaaehtoista. Voitte kieltäytyä osallistumasta opinnäytetyöhön tai peruuttaa osallistumisenne syytä ilmoittamatta milloin tahansa ilman seuraamuksia. Kieltäytyminen ei vaikuta saamaanne hoitoon.

Lukekaa rauhassa tämä tiedote. Jos teillä on kysyttävää opinnäytetyöstä, voitte olla yhteydessä opinnäytetyöntekijöihin tiedotteesta löytyvin yhteystiedoin.

Jos päätätte osallistua opinnäytetyöhön, Teitä pyydetään allekirjoittamaan viimeisellä sivulla oleva suostumus ja olemaan yhteydessä opinnäytetyöntekijöihin.

Opinnäytetyön tausta ja tarkoitus

Tämä opinnäytetyön tarkoitus on tutkia, kuinka perhelähtöinen hoitotyö toteutuu kotiutussuunnitelman avulla KYS Vastasyntyneiden teho-osastolla. Tavoite on, että opinnäytetyön avulla voidaan kehittää perhelähtöistä hoitotyötä keskosten hoidossa.

Tulevaisuudessa opinnäytetyön tuloksia on tarkoitus hyödyntää digihoitopolun kehittämisessä KYS vastasyntyneiden teho-osastolle. Digihoitopolku on Terveyskylässä sijaitseva digitaalinen alusta, joka on tarkoitettu hoidon tueksi potilaille ja perheille. Suomessa Vastasyntyneiden teho-osastoilla ei ole käytössä vielä yhtään digihoitopolkua.

Osana opinnäytetyön toteutusta toivotaan, että vanhemmat kertoisivat opinnäytetyöntekijöille hoitojaksostaan KYSin Vastasyntyneiden teho-osastolla. Tämä tapahtuu teemahaastatteluna. Teemat haastattelua varten ovat muodostuneet tämänhetkisen keskosen ohjausmateriaalin ja hoitopolun mukaan. Haastattelun teemat löytyvät tämän tiedotteen lopusta. Teemahaastattelussa opinnäytetyöntekijät ohjaavat keskustelua ja kysyvät Teiltä kysymyksiä. Haastattelu on kuitenkin vapaamuotoinen.

Opinnäytetyöhön osallistuvien määrää ei ole rajoitettu. Opinnäytetyöhön toivotaan osallistuvan vähintään viisi perhettä. Opinnäytetyöhön voi osallistua molemmat vanhemmat tai vain toinen vanhempi.

Opinnäytetyöhön osallistuminen

Mikäli päätätte osallistua opinnäytetyöhön, Teitä pyydetään allekirjoittamaan viimeisellä sivulla oleva suostumus ja olemaan tämän jälkeen yhteydessä opinnäytetyöntekijöihin joko sähköpostitse tai tekstiviestillä. Opinnäytetyöntekijät sopivat kanssanne opinnäytetyöhön osallistumisen ajankohdan, keräävät allekirjoitetut suostumukset sekä antavat Teille kopion allekirjoitetusta suostumuksesta.

Opinnäytetyöhön osallistuminen tapahtuu kertaluontoisesti. Voitte osallistua Teille sopivana ajankohtana joko hoitojaksonne aikana KYSin Vastasyntyneiden teho-osaston perhehuoneessa tai kotiutumisenne jälkeen yhteisesti sovitussa paikassa. Myös etäyhteydellä (Teams/puhelu) osallistuminen on mahdollista, kuitenkin viimeistään sinä päivänä, joka tässä tiedotteessa on ilmoitettu.

Haastattelut nauhoitetaan erillisellä laitteella. Lisäksi opinnäytetyöntekijät voivat tehdä muistiinpanoja haastattelun aikana paperille. Haastattelun aikana kertomanne asiat, antamanne kehitysehdotukset tai palaute eivät vaikuta saamaanne hoitoon KYSin Vastasyntyneiden teho-osastolla. Tietoja käytetään materiaalina vain tässä opinnäytetyössä ja vain siihen kehittämistarkoitukseen, joka tiedotteessa on mainittu. Haastattelut ovat täysin luottamuksellisia ja nimettömiä, ja toivommekin avointa keskustelua kokemuksistanne.

Halutessanne voitte jättää vastaamatta mihin tahansa kysymykseen tai keskeyttää haastattelun. Mikäli haluatte keskeyttää haastattelun, osallistumisenne opinnäytetyöhön katsotaan päättyneeksi ja tähän asti kerättyä materiaalia voidaan käyttää opinnäytetyössä. Teillä on oikeus tässä vaiheessa myös perua osallistumisenne opinnäytetyöhön, jolloin kerättyä materiaalia ei käytetä.

Opinnäytetyön mahdolliset hyödyt

Perhelähtöisen hoitotyön myötä vanhemmat ovat keskosen hoidossa tärkeimmässä roolissa vastasyntyneiden teho-osastolla. Opinnäytetyön tavoitteena on kehittää perhelähtöistä hoitotyötä KYSin Vastasyntyneiden teho-osastolla digitalisaation avulla. Tavoitteena on, että ottamalla keskosten vanhemmat mukaan uuden digitaalisen hoitopolun suunnittelutyöhön alusta alkaen luodaan kokonaisuus, joka on paras mahdollinen perheiden näkökulmasta ja tukee vanhempien roolia oman vauvansa hoidossa entistä enemmän.

Opinnäytetyön tulokset voivat mahdollistaa entistä yksilöllisemmän hoitopolun luomisen digihoitopolun muodossa sekä vastata paremmin vanhempien tarpeisiin. Digihoitopolku voisi tuoda vanhemmille entistä ajantasaisempaa, keskeytyksettömämpää tietoa oman vauvan hoidosta ja suunnitelmista. Digihoitopolun avulla tiedon saavutettavuus tulevaisuudessa paranee, kun tiedonsaanti ei ole riippuvaista ajasta tai paikasta. Tavoitteena on taata kaikille keskosperheille yhdenvertainen mahdollisuus tietoon ja tukeen hoitojakson aikana.

Opinnäytetyön mahdolliset haitat

Opinnäytetyöprosessista ei ole odotettavissa haittoja tutkimukseen osallistuville perheille.

Tietojen luottamuksellisuus ja tietosuoja

Teiltä kerätään vain tämän opinnäytetyön toteuttamiseen tarvittavat välttämättömät henkilötiedot. Tämä tarkoittaa käytännössä tähän suostumuslomakkeeseen annettavaa allekirjoitusta ja nimenselvennöstä sekä yhteystietoja. Kerättävistä lomakkeista muodostuu opinnäytetyön tutkimusrekisteri. Opinnäytetyön teemahaastatteluissa tuotettava materiaali on nimetöntä alusta alkaen.

Opinnäytetyöhön osallistuvat vanhemmat saavat kopion allekirjoitetusta suostumuslomakkeesta. Alkuperäinen allekirjoitettu suostumuslomake jää opinnäytetyöntekijöille. Suostumuslomakkeet säilytetään KYSin Vastasyntyneiden teho-osaston hallinnon tiloissa, lukitussa huoneessa. Niihin katseluoikeus on ainoastaan opinnäytetyöntekijöillä. Opinnäytetyöhön osallistuvien henkilöllisyydet ovat ainoastaan opinnäytetyöntekijöiden ja mahdollisesti Teitä hoitavan henkilökunnan jäsenten tiedossa ja kaikki ovat salassapitovelvollisia.

Opinnäytetyötä varten kerättyä aineistoa käytetään opinnäytetyössä koodattuna, esim. ”vanhempi 1” tai ”perhe 2”. Kaikki yksilöivät tunnisteet korvataan/poistetaan. Henkilöitä ei voida tunnistaa opinnäytetyöhön liittyvistä tutkimustuloksista tai muista siihen liittyvistä julkaisuista. Opinnäytetyön teemahaastattelussa muodostuneet nauhoitteet ja muistiinpanot kirjoitetaan puhtaaksi nimettömästi Word-asiakirjaan, joka tallennetaan tietokoneelle suljettuun opinnäytetyöntekijöiden Microsoft Teams-ryhmään opinnäytetyöprosessin ajaksi. Kuunteluoikeus nauhoitteisiin on ainoastaan opinnäytetyöntekijöillä. Haastatteluissa käytettävä nauhuri säilytetään KYSin Vastasyntyneiden teho-osaston hallinnon tiloissa, lukitussa huoneessa.

Opinnäytetyöntekijät säilyttävät allekirjoitettuja suostumuslomakkeita, nauhoitettuja haastatteluita, puhtaaksikirjoitettuja haastatteluita ja muita muistiinpanoja opinnäytetyön julkaisuun asti. Julkaisemisen jälkeen kaikki paperiset lomakkeet hävitetään asianmukaisesti salaisen paperijätteen mukana KYSissä. Nauhoitteet poistetaan nauhurista. Sähköiset, puhtaaksikirjoitetut Word-asiakirjat poistetaan tietokoneelta.

Tässä opinnäytetyössä noudatetaan tietosuojaperiaatteita, jotka löydätte täältä: https://tietosuoja.fi/tietosuojaperiaatteet. ”Tietosuojaperiaatteita on noudatettava aina, kun käsitellään henkilötietoja. Rekisterinpitäjän on myös pystyttävä osoittamaan, että tietosuojaperiaatteet toteutuvat tehokkaasti henkilötietojen käsittelyssä.” Tietosuojaperiaatteet perustuvat EU:n yleiseen tietosuoja-asetukseen, jonka tarkoituksena on antaa parempi suoja henkilötiedoille ja niiden käsittelyyn. EU:n yleinen tietosuoja-asetus löytyy EUR-Lexin verkkosivuilta: https://eur-lex.europa.eu/legal-content/FI/TXT/HTML/?uri=CELEX:32016R0679&from=FI.

SUOSTUMUS OSALLISTUMISESTA OPINNÄYTETYÖHÖN

Minua on pyydetty osallistumaan opinnäytetyöhön perhelähtöisen hoitotyön kehittämisestä KYSin Vastasyntyneiden teho-osastolle. Olen perehtynyt opinnäytetyöstä annettuun tiedotteeseen ja saanut riittävästi tietoa opinnäytetyön tarkoituksesta ja roolistani siinä, sekä opinnäytetyön yhteydessä suoritettavasta tietojen keräämisestä, käsittelystä ja hävittämisestä.

Minulla on ollut riittävästi aikaa harkita opinnäytetyöhön osallistumista. Minulle on kerrottu opinnäytetyöstä ja sen sisällöstä myös suullisesti ja olen saanut riittävän vastauksen kaikkiin esittämiini kysymyksiin. Tarvittaessa lisätietoa opinnäytetyöstä antoi: ___________________________.

Minulla on oikeus, milloin tahansa opinnäytetyön aikana ja syytä ilmoittamatta keskeyttää osallistumiseni. Keskeytyksestä ei aiheudu minulle haittaa tai kielteisiä seuraamuksia eikä se vaikuta hoitoon KYSin Vastasyntyneiden teho-osastolla. Olen tietoinen siitä, että keskeyttämiseeni mennessä kerättyjä tietoja voidaan kuitenkin käyttää osana opinnäytetyön aineistoa. Mikäli perun osallistumiseni opinnäytetyöhön, kerättyjä tietoja ei käytetä opinnäytetyössä.

Allekirjoituksellani vahvistan, että osallistun tässä tiedotteessa kuvattuun opinnäytetyöhön ja suostun haastateltavaksi.

______________________________	______________________________
Allekirjoitus	Nimen selvennys
______________________________	______________________________
Aika ja paikka	Puhelinnumero ja / tai sähköpostiosoite

Suostumus vastaanotettu

______________________________	______________________________
Vastaanottajan allekirjoitus	Nimen selvennys
______________________________	
Aika ja paikka	

Alkuperäinen allekirjoitettu suostumus jää opinnäytetyöntekijöille opinnäytetyöprosessin ajaksi ja kopio asiakirjasta annetaan opinnäytetyön osallistujalle. Tiedot suostumusten säilyttämisestä ja hävittämisestä löytyvät tämän suostumuslomakkeen mukana tulleesta tiedotteesta ja tarvittaessa opinnäytetyöntekijät antavat lisätietoa.

Viimeinen mahdollinen teemahaastattelun toteutuspäivä on 31.12.2022.

TIEDOTE OPINNÄYTETYÖSTÄ SAIRAANHOITAJILLE:

DIGIHOITOPOLUN KEHITTÄMINEN KYSIN VASTASYNTYNEIDEN TEHO-OSASTOLLA

Teitä pyydetään mukaan opinnäytetyöhön, joka keskittyy digihoitopolun kehittämiseen KYSin Vastasyntyneiden teho-osastolla. Olemme arvioineet, että soveltuisitte opinnäytetyöhön, sillä olette työskennelleet KYS Vastasyntyneiden teho-osastolla vähintään kahden vuoden ajan ja olette osallistuneet alle 34 raskausviikolla syntyneiden keskosten hoitoon. Tämä tiedote kuvaa opinnäytetyön tarkoitusta ja toteutusta sekä Teidän mahdollista osuuttanne siinä. Tämä tiedote annetaan luettavaksi kaikille hoitajille, joiden on arvioitu soveltuvan opinnäytetyöhön. Tämän tiedotteen antaminen Teille ei ole edellyttänyt henkilötietojen keräämistä.

Osallistuminen opinnäytetyöhön on vapaaehtoista. Voitte kieltäytyä osallistumasta opinnäytetyöhön tai peruuttaa osallistumisenne syytä ilmoittamatta milloin tahansa ilman seuraamuksia. Kieltäytyminen ei vaikuta työskentelyynne Vastasyntyneiden teho-osastolla.

Lukekaa rauhassa tämä tiedote. Jos teillä on kysyttävää opinnäytetyöstä, voitte olla yhteydessä opinnäytetyöntekijöihin tiedotteesta löytyvin yhteystiedoin. Jos päätätte osallistua opinnäytetyöhön, Teitä pyydetään allekirjoittamaan viimeisellä sivulla oleva suostumus ja olemaan yhteydessä opinnäytetyöntekijöihin.

Opinnäytetyön tausta ja tarkoitus

Tämän opinnäytetyön tarkoitus on kehittää sisältöä ja rakennetta digihoitopolulle, jota käytettäisiin tulevaisuudessa keskosten hoidossa KYSin Vastasyntyneiden teho-osastolla. Digihoitopolku on Terveyskylässä sijaitseva digitaalinen alusta.

Osana opinnäytetyön toteutusta toivotaan, että sairaanhoitajat kertoisivat opinnäytetyöntekijöille keskosen hoitopolusta ja kotiutussuunnitelman käytöstä KYSin Vastasyntyneiden teho-osastolla. Lisäksi tarkoituksena on selvittää, mitä sairaanhoitajat pitävät tärkeänä digihoitopolun sisällön suhteen. Tämä tapahtuu teemahaastatteluna. Teemat haastattelua varten ovat muodostuneet tämänhetkisen keskosen ohjausmateriaalin ja hoitopolun mukaan. Haastattelun teemat löytyvät tämän tiedotteen lopusta. Teemahaastattelussa opinnäytetyöntekijät ohjaavat keskustelua ja kysyvät Teiltä kysymyksiä. Haastattelu on kuitenkin vapaamuotoinen.

Opinnäytetyöhön osallistuvien määrää ei ole rajoitettu.

Opinnäytetyöhön osallistuminen

Mikäli päätätte osallistua opinnäytetyöhön, Teitä pyydetään allekirjoittamaan viimeisellä sivulla oleva suostumus ja olemaan tämän jälkeen yhteydessä opinnäytetyöntekijöihin. Opinnäytetyöntekijät keräävät allekirjoitetut suostumukset ja sopivat kanssanne opinnäytetyöhön osallistumisen ajankohdan.

Opinnäytetyöhön osallistuminen tapahtuu kertaluontoisesti. Voitte osallistua Teille sopivana ajankohtana.

Haastattelut nauhoitetaan erillisellä laitteella. Lisäksi opinnäytetyöntekijät voivat tehdä muistiinpanoja haastattelun aikana paperille. Haastattelun aikana kertomanne asiat ja antamanne kehitysehdotukset käsitellään luottamuksellisesti. Tietoja käytetään materiaalina vain tässä opinnäytetyössä ja vain siihen kehittämistarkoitukseen, joka tiedotteessa on mainittu. Toivommekin avointa keskustelua kokemuksistanne.

Halutessanne voitte jättää vastaamatta mihin tahansa kysymykseen tai keskeyttää haastattelun. Mikäli haluatte keskeyttää haastattelun, osallistumisenne opinnäytetyöhön katsotaan päättyneeksi ja tähän asti kerättyä materiaalia voidaan käyttää opinnäytetyössä. Teillä on oikeus tässä vaiheessa myös perua osallistumisenne opinnäytetyöhön, jolloin kerättyä materiaalia ei käytetä.

Opinnäytetyön mahdolliset hyödyt

Opinnäytetyön tulokset voivat mahdollistaa entistä yksilöllisemmän hoitopolun luomisen digihoitopolun muodossa sekä vastata paremmin vanhempien tarpeisiin. Digihoitopolku voisi tuoda vanhemmille entistä ajantasaisempaa, keskeytyksettömämpää tietoa oman vauvansa hoidosta ja suunnitelmista. Digihoitopolun avulla tiedon saavutettavuus tulevaisuudessa paranee, kun tiedonsaanti ei ole riippuvaista ajasta tai paikasta. Tavoitteena on taata kaikille keskosperheille yhdenvertainen mahdollisuus tietoon ja tukeen hoitojakson aikana. Sairaanhoitajat ovat keskeisessä roolissa perhelähtöisen hoitotyön toteuttajina.

Opinnäytetyön mahdolliset haitat

Opinnäytetyöprosessista ei ole odotettavissa haittoja tutkimukseen osallistuville.

Tietojen luottamuksellisuus ja tietosuoja

Teiltä kerätään vain tämän opinnäytetyön toteuttamiseen tarvittavat välttämättömät henkilötiedot. Tämä tarkoittaa käytännössä tähän suostumuslomakkeeseen annettavaa allekirjoitusta ja nimenselvennöstä. Kerättävistä lomakkeista muodostuu opinnäytetyön tutkimusrekisteri. Opinnäytetyön teemahaastatteluissa tuotettava materiaali on nimetöntä alusta alkaen.

Opinnäytetyöhön osallistuvat saavat kopion allekirjoitetusta suostumuslomakkeesta. Alkuperäinen allekirjoitettu suostumuslomake jää opinnäytetyöntekijöille. Suostumuslomakkeet säilytetään KYSin Vastasyntyneiden teho-osaston hallinnon tiloissa, lukitussa huoneessa. Niihin katseluoikeus on ainoastaan opinnäytetyöntekijöillä. Opinnäytetyöhön osallistuvien henkilöllisyydet ovat ainoastaan opinnäytetyöntekijöiden tiedossa.

Opinnäytetyötä varten kerättyä aineistoa käytetään opinnäytetyössä koodattuna. Kaikki yksilöivät tunnisteet korvataan/poistetaan. Henkilöitä ei voida tunnistaa opinnäytetyöhön liittyvistä tutkimustuloksista tai muista siihen liittyvistä julkaisuista. Opinnäytetyön teemahaastattelussa muodostuneet nauhoitteet ja muistiinpanot kirjoitetaan puhtaaksi nimettömästi Word-asiakirjaan, joka tallennetaan tietokoneelle suljettuun opinnäytetyöntekijöiden Microsoft Teams-ryhmään opinnäytetyöprosessin ajaksi. Kuunteluoikeus nauhoitteisiin on ainoastaan opinnäytetyöntekijöillä. Haastatteluissa käytettävä nauhuri säilytetään KYSin Vastasyntyneiden teho-osaston hallinnon tiloissa, lukitussa huoneessa.

Opinnäytetyöntekijät säilyttävät allekirjoitettuja suostumuslomakkeita, nauhoitettuja haastatteluita, puhtaaksikirjoitettuja haastatteluita ja muita muistiinpanoja opinnäytetyön julkaisuun asti. Julkaisemisen jälkeen kaikki paperiset lomakkeet hävitetään asianmukaisesti salaisen paperijätteen mukana KYSissä. Nauhoitteet poistetaan nauhurista. Sähköiset, puhtaaksikirjoitetut Word-asiakirjat poistetaan tietokoneelta.

> *Tässä opinnäytetyössä noudatetaan tietosuojaperiaatteita, jotka löydätte täältä: https://tietosuoja.fi/tietosuojaperiaatteet. "Tietosuojaperiaatteita on noudatettava aina, kun käsitellään henkilötietoja. Rekisterinpitäjän on myös pystyttävä osoittamaan, että tietosuojaperiaatteet toteutuvat tehokkaasti henkilötietojen käsittelyssä." Tietosuojaperiaatteet perustuvat EU:n yleiseen tietosuoja-asetukseen, jonka tarkoituksena on antaa parempi suoja henkilötiedoille ja niiden käsittelyyn. EU:n yleinen tietosuoja-asetus löytyy EUR-Lexin verkkosivuilta: https://eur-lex.europa.eu/legalcontent/FI/TXT/HTML/?uri=CELEX:32016R0679&from=FI.*

SUOSTUMUS OSALLISTUMISESTA OPINNÄYTETYÖHÖN

Minua on pyydetty osallistumaan opinnäytetyöhön digihoitopolun kehittämisestä KYSin Vastasyntyneiden teho-osastolle. Olen perehtynyt opinnäytetyöstä annettuun tiedotteeseen ja saanut riittävästi tietoa opinnäytetyön tarkoituksesta ja roolistani siinä, sekä opinnäytetyön yhteydessä suoritettavasta tietojen keräämisestä, käsittelystä ja hävittämisestä.

Minulla on ollut riittävästi aikaa harkita opinnäytetyöhön osallistumista. Minulle on kerrottu opinnäytetyöstä ja sen sisällöstä myös suullisesti ja olen saanut riittävän vastauksen kaikkiin esittämiini kysymyksiin. Tarvittaessa lisätietoa opinnäytetyöstä antoi: ___________________________.

Minulla on oikeus, milloin tahansa opinnäytetyön aikana ja syytä ilmoittamatta keskeyttää osallistumiseni. Keskeytyksestä ei aiheudu minulle haittaa tai kielteisiä seuraamuksia. Olen tietoinen siitä, että keskeyttämiseeni mennessä kerättyjä tietoja voidaan kuitenkin käyttää osana opinnäytetyön aineistoa. Mikäli perun osallistumiseni opinnäytetyöhön, kerättyjä tietoja ei käytetä opinnäytetyössä.

Allekirjoituksellani vahvistan, että osallistun tässä tiedotteessa kuvattuun opinnäytetyöhön ja suostun haastateltavaksi.

______________________________	______________________________
Allekirjoitus	Nimen selvennys
______________________________	______________________________
Aika ja paikka	Puhelinnumero ja / tai sähköpostiosoite

Suostumus vastaanotettu

______________________________	______________________________
Vastaanottajan allekirjoitus	Nimen selvennys
______________________________	
Aika ja paikka	

Alkuperäinen allekirjoitettu suostumus jää opinnäytetyöntekijöille opinnäytetyöprosessin ajaksi ja kopio asiakirjasta annetaan opinnäytetyön osallistujalle. Tiedot suostumusten säilyttämisestä ja hävittämisestä löytyvät tämän suostumuslomakkeen mukana tulleesta tiedotteesta ja tarvittaessa opinnäytetyöntekijät antavat lisätietoa.

APPENDIX 4: THEMATIC INTERVIEW

TEEMAHAASTATTELU

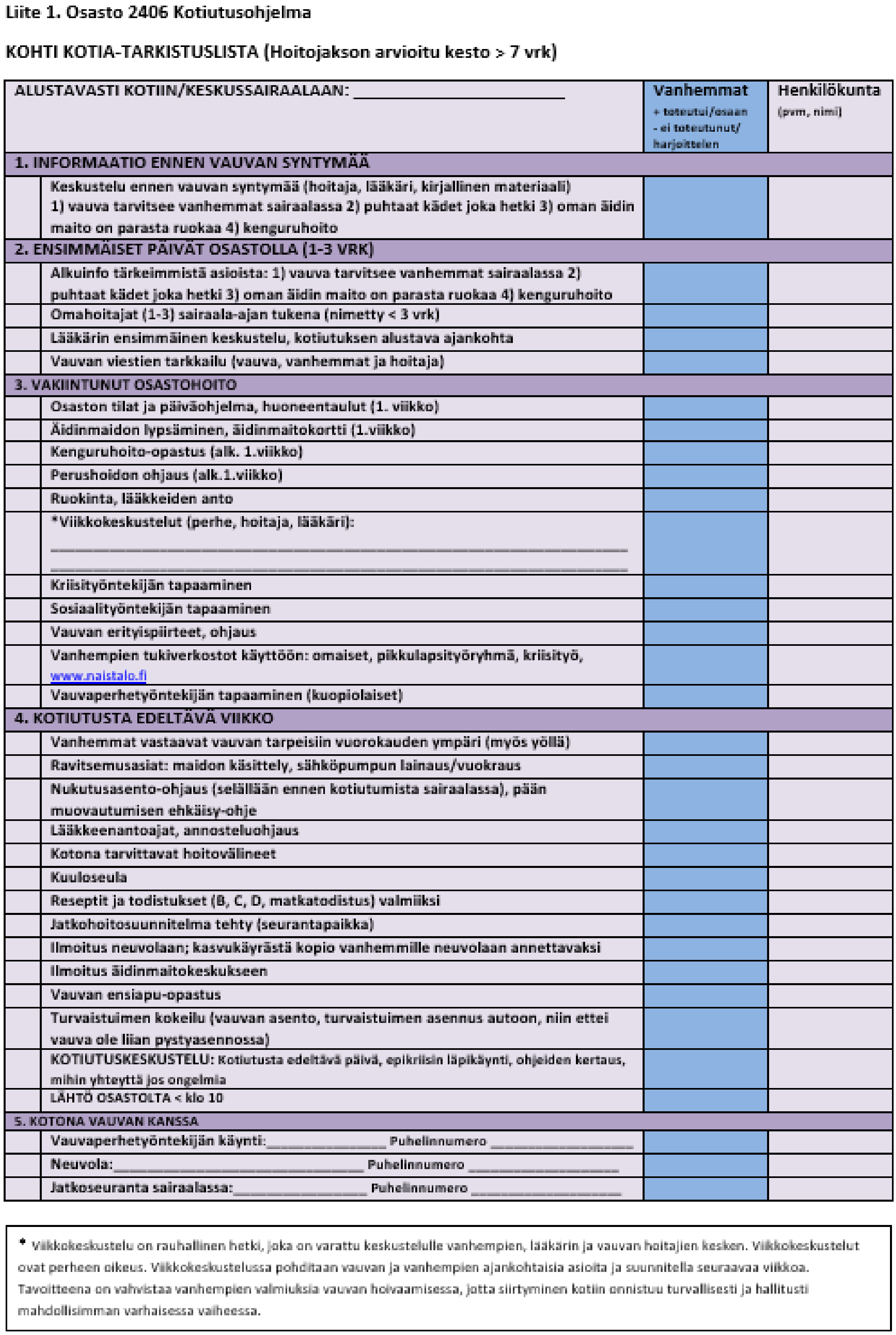
Olette saaneet KYS Vastasyntyneiden teho-osastolla käytettävän kotiutussuunnitelman liitteineen itsellenne katsottavaksi. Tutustukaa kotiutussuunnitelman sisältöön. Teemahaastattelussa käydään läpi kotiutussuunnitelmaa, sen toimivuutta ja Teidän kokemuksianne sen käytettävyydestä ajatellen digihoitopolkua.

Teemahaastattelussa on tarkoituksena keskustella avoimesti ennalta sovituista teemoista. Tämän haastattelun teemat pohjautuvat paitsi käytössä olevaan kotiutussuunnitelmaan, myös perhelähtöisen hoitotyön osa-alueisiin. Teemahaastattelussa ei ole tarkkaa etenemisreittiä, eikä kaikista teemoista tarvitse keskustella samassa laajuudessa. Tarkoituksena kuitenkin on, että kaikki teemat käydään läpi kaikissa haastatteluissa. Teemahaastattelussa korostuu Teidän omat kokemuksenne, tulkintanne eri tilanteista sekä asiat, jotka Te olette kokeneet merkityksellisinä. Jokainen kokemus on arvokas, eikä teemahaastatteluissa ole oikeita tai vääriä vastauksia.

Teemahaastattelun teemat:

1. Keskosen hoitopolun kuvaaminen KYSin Vastasyntyneiden teho-osastolla
2. Nykyisen kotiutussuunnitelman käytettävyys perhelähtöisessä hoitotyössä
3. Kotiutussuunnitelman käytettävyys tulevalla digihoitopolulla
4. Tärkeäksi koettu sisältö tulevalla digihoitopolulla

APPENDIX 5: THE KUH NICU DISCHARGE PLAN



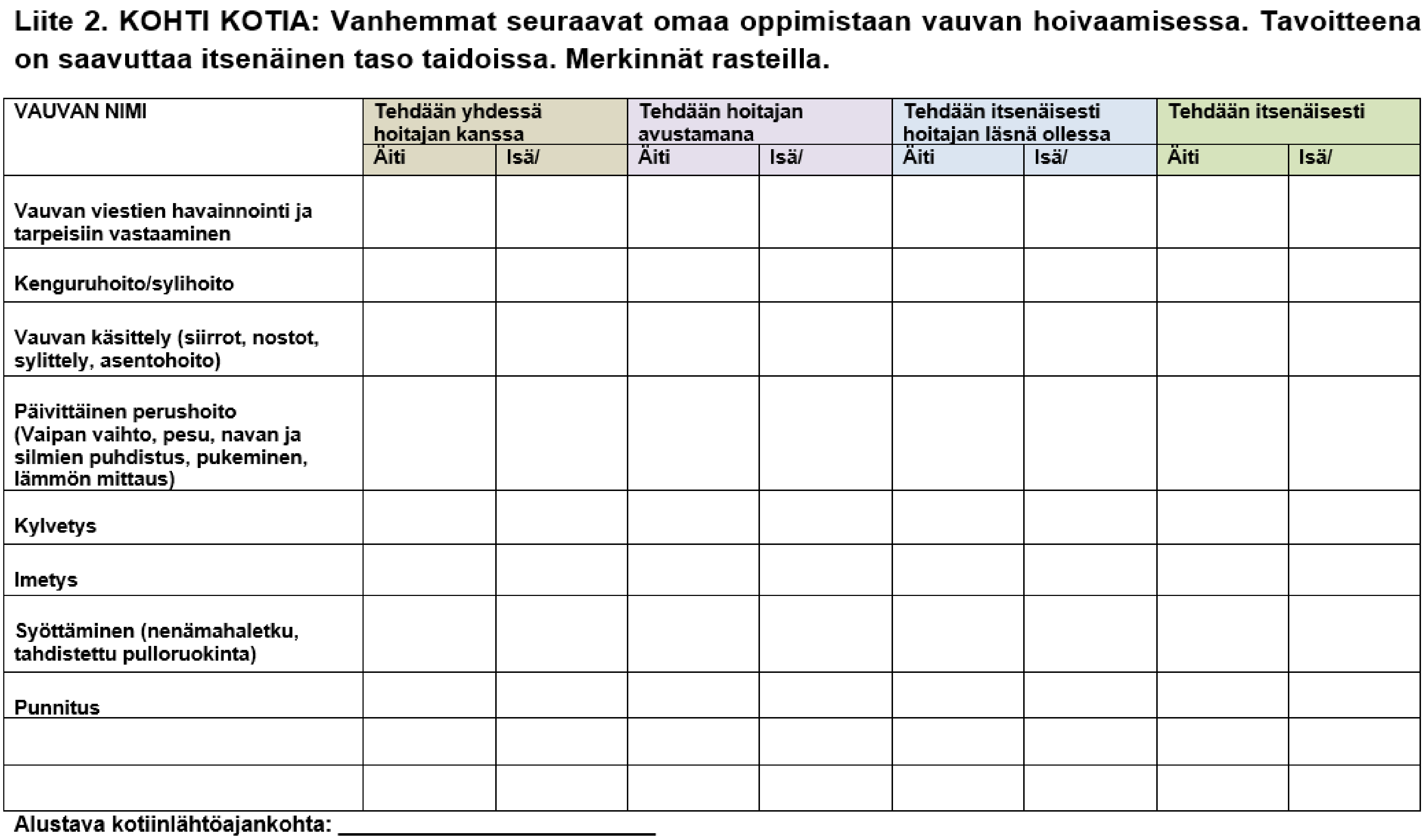
Liite 1. Osasto 2406 Kotiutusohjelma

KOHTI KOTIA-TARKISTUSLISTA (Hoitojakson arvioitu kesto > 7 vrk)

ALUSTAVASTI KOTIIN/KESKUSSAIRAALAAN: ______________________		Vanhemmat + toteutui/osaan - ei toteutunut/ harjoittelen	Henkilökunta (pvm, nimi)
1. INFORMAATIO ENNEN VAUVAN SYNTYMÄÄ			
	Keskustelu ennen vauvan syntymää (hoitaja, lääkäri, kirjallinen materiaali) 1) vauva tarvitsee vanhemmat sairaalassa 2) puhtaat kädet joka hetki 3) oman äidin maito on parasta ruokaa 4) kenguruhoito		
2. ENSIMMÄISET PÄIVÄT OSASTOLLA (1-3 VRK)			
	Alkuinfo tärkeimmistä asioista: 1) vauva tarvitsee vanhemmat sairaalassa 2) puhtaat kädet joka hetki 3) oman äidin maito on parasta ruokaa 4) kenguruhoito		
	Omahoitajat (1-3) sairaala-ajan tukena (nimetty < 3 vrk)		
	Lääkärin ensimmäinen keskustelu, kotiutuksen alustava ajankohta		
	Vauvan viestien tarkkailu (vauva, vanhemmat ja hoitaja)		
3. VAKIINTUNUT OSASTOHOITO			
	Osaston tilat ja päiväohjelma, huoneentaulut (1. viikko)		
	Äidinmaidon lypsäminen, äidinmaitokortti (1.viikko)		
	Kenguruhoito-opastus (alk. 1.viikko)		
	Perushoidon ohjaus (alk.1.viikko)		
	Ruokinta, lääkkeiden anto		
	*Viikkokeskustelut (perhe, hoitaja, lääkäri): ____ ____		
	Kriisityöntekijän tapaaminen		
	Sosiaalityöntekijän tapaaminen		
	Vauvan erityispiirteet, ohjaus		
	Vanhempien tukiverkostot käyttöön: omaiset, pikkulapsityöryhmä, kriisityö, www.naistalo.fi		
	Vauvaperhetyöntekijän tapaaminen (kuopiolaiset)		
4. KOTIUTUSTA EDELTÄVÄ VIIKKO			
	Vanhemmat vastaavat vauvan tarpeisiin vuorokauden ympäri (myös yöllä)		
	Ravitsemusasiat: maidon käsittely, sähköpumpun lainaus/vuokraus		
	Nukutusasento-ohjaus (selällään ennen kotiutumista sairaalassa), pään muovautumisen ehkäisy-ohje		
	Lääkkeenantoajat, annosteluohjaus		
	Kotona tarvittavat hoitovälineet		
	Kuuloseula		
	Reseptit ja todistukset (B, C, D, matkatodistus) valmiiksi		
	Jatkohoitosuunnitelma tehty (seurantapaikka)		
	Ilmoitus neuvolaan; kasvukäyrästä kopio vanhemmille neuvolaan annettavaksi		
	Ilmoitus äidinmaitokeskukseen		
	Vauvan ensiapu-opastus		
	Turvaistuimen kokeilu (vauvan asento, turvaistuimen asennus autoon, niin ettei vauva ole liian pystyasennossa)		
	KOTIUTUSKESKUSTELU: Kotiutusta edeltävä päivä, epikriisin läpikäynti, ohjeiden kertaus, mihin yhteyttä jos ongelmia		
	LÄHTÖ OSASTOLTA < klo 10		
5. KOTONA VAUVAN KANSSA			
	Vauvaperhetyöntekijän käynti:______________ Puhelinnumero _________________		
	Neuvola:______________________________ Puhelinnumero _________________		
	Jatkoseuranta sairaalassa:_______________ Puhelinnumero _________________		

* Viikkokeskustelu on rauhallinen hetki, joka on varattu keskustelulle vanhempien, lääkärin ja vauvan hoitajien kesken. Viikkokeskustelut ovat perheen oikeus. Viikkokeskustelussa pohditaan vauvan ja vanhempien ajankohtaisia asioita ja suunnitella seuraavaa viikkoa. Tavoitteena on vahvistaa vanhempien valmiuksia vauvan hoivaamisessa, jotta siirtyminen kotiin onnistuu turvallisesti ja hallitusti mahdollisimman varhaisessa vaiheessa.

APPENDIX 6: JOURNEY TO HOME



Liite 2. KOHTI KOTIA: Vanhemmat seuraavat omaa oppimistaan vauvan hoivaamisessa. Tavoitteena on saavuttaa itsenäinen taso taidoissa. Merkinnät rasteilla.

VAUVAN NIMI	Tehdään yhdessä hoitajan kanssa		Tehdään hoitajan avustamana		Tehdään itsenäisesti hoitajan läsnä ollessa		Tehdään itsenäisesti	
	Äiti	Isä/	Äiti	Isä/	Äiti	Isä/	Äiti	Isä/
Vauvan viestien havainnointi ja tarpeisiin vastaaminen								
Kenguruhoito/sylihoito								
Vauvan käsittely (siirrot, nostot, sylittely, asentohoito)								
Päivittäinen perushoito (Vaipan vaihto, pesu, navan ja silmien puhdistus, pukeminen, lämmön mittaus)								
Kylvetys								
Imetys								
Syöttäminen (nenämahaletku, tahdistettu pulloruokinta)								
Punnitus								

Alustava kotiinlähtöajankohta: ___________________________

APPENDIX 7: A WEEK IN THE FAMILY ROOM

Liite 4 **Meidän viikkomme perhehuoneessa**

Viikon tavoite on: ____

Viikko no ___	Maanantai	Tiistai	Keskiviikko	Torstai	Perjantai	Lauantai	Sunnuntai
Päivän "ohjelma"							
Päivän tavoite							
Tutkimukset							
Keskustelut							
Muuta							
Imetys/ lypsäminen							
Millainen päivä? ☹ 😐 ☺							

Kotiutumisen alustava ajankohta: __________

APPENDIX 8: EXAMPLES OF FAMILY ROOM FORMS

VAUVAN SEURANTA PERHEHUONEESSA

Nimi: _______________ Huoneen numero: ____

VIIKKOMITAT
Pvm:
Paino:
Pituus:
Päänympärys:

Pvm.	Klo	Paino	Lämpö	Virtsa	Vatsan toiminta	Saturaatio-mittarin paikan vaihto

	Syöttöpunnitus				
Klo	Alkupaino	Loppupaino	Rinnalta	Syöttö-letkuun	Pullosta

Kenguru/ihokontakti	
Alkoi	Loppui

VAUVAN SEURANTA PERHEHUONEESSA

Nimi: _______________ Huoneen numero: ____

VIIKKOMITAT
Pvm:
Paino:
Pituus:
Päänympärys:

Pvm	Klo	Paino	Lämpö	Virtsa	Vatsan toiminta	Muut huomiot

	Syöttöpunnitus				
Klo	Alkupaino	Loppupaino	Rinnalta	Syöttö-letkuun	Pullosta

Kenguru/ihokontakti	
Alkoi	Loppui

	Stoomaerite			
Klo	Tullut	Siirretty	Siirtämättä	Pussinvaihto
			=	
			=	
			=	
			=	
			=	
			=	

	Stoomaerite			
Klo	Tullut	Siirretty	Siirtämättä	Pussinvaihto
			=	
			=	
			=	
			=	
			=	
			=	

	Stoomaerite			
Klo	Tullut	Siirretty	Siirtämättä	Pussinvaihto
			=	
			=	
			=	
			=	
			=	
			=	

APPENDIX 9: CONTENT ANALYSIS PROCESS EXAMPLE

Transcription	**REDUCTION**	**LOWER CLASS**	**UPPER CLASS**	**MAIN CLASS**
“jos siinä on niitä - tuttuja hoitajia, niin niille ehkä herkemmin, kun sitten taas jos on joku semmoinen ihminen joka ei siinä ole paljon ollut niin se asia menee herkemmin sitten tavallaan seuraavassa vuorossa jos on taas se omahoitaja niin se omahoitajan korviin että me oltaisiin haluttu tehdä näin, mutta tää teki näin tai muuta vastaavaa” *“en olekaan omahoitaja niin en lähde käymään asioita läpi, en lähde ohjailemaan heitä millään tavalla, vaan enemmän myöteillen, annan vinkkejä jos haluavat, tuen”* *“ihan inhimillistähän se on, mut semmoista hoitajariippuvaista, että niille omille hoitajille perheille on ehkä helpoin lähestyä niinku semmoisissa vaikeissa asioissa.”* *“Siellähän on ollu välillä pitkiäkin hoitojaksoja niinku kuitenkin viikkoja. Vaikka kuukauskin ja ei oo omahoitajaa ollenkaan. Et ei se toteudu kaikkien kohalla. Osahan saa heti kun osastolle tulee, niin saa omahoitajan välittömästi siinä hetkessä, mut sit osalle ei niinkun löydy.”* *“Ihan yksittäiset perheet on saattanu kysyä, et miks meillä ei oo omahoitajaa.. ”* *“No tällä hetkellä ei (toteudu). Tai niin, vähän.”* *“Niillä ihan pienemmillä ja pitkäaikaisilla on niitä omahoitajia hyvinkin.”* *“No valitettavasti silloin kun jos rupeaa jollekin pienelle omahoitajaksi, niin eihän se siinä lähellä laskettua aikaa enää toteudu.”* *“Itse olin kovin närkästynyt, kun en oo ollut pitkään aikaan omahoitaja ja aloin, niin en päässy ollenkaan. Pyritäänhän siihen toki, mutta ei se ehkä oo tasalaatuista aina.”* *“Osa saa olla ja osa ei saa koskaan”* *“Kyllä mä silti sanoisin että pääosin joo - luonnollisestikin se syy, että meillä ei riitä kolmostason hoitajat siihen, että kolmostason hoitaja vois hoitaa semmoista kotiutuvaa ykköstason lasta, joka on lähinnä pääosin niinku vanhempien hoidettavissa oleva tai et vanhemmat hoitaa vaan sitten ne kolmostason osaajat tarvitaan jo sitten sinne seuraavien raskasta tehohoitoa vaativien potilaiden hoitoon.”* *“kun pari päivää olen ollu sitten muualla hoitamassa ja ei oo ollu omahoitaja edes hoitamassa niin niin, sitten kun on käyny siinä tai kävelly niin ‘miks et oo’ et ‘miks sä oot muualla’ kyllä ne kattoo jos se omahoitaja ei ookkaan heijän hoitaja ja se kävelee tuolla maa… menee naapurihuoneeseen tai muuta” “kyllä näki, et oot töissä mut oot muissa töissä, he varmaan tyytyy siihen hetkeen ja kun käy vaihtamassa kuulumisia”* *“ne osoittaa sen kyllä jotenkin, että ei ole sinua näkynyt - jos en oo päässyt, oon käynyt juttelemassa ja koen, että hyö on kovin kiitollisia edes siitä hetkestä”* *“No osittain.. niinku toteutuu. Ja varsinkin siinä alkuvaiheessa ehkä enemmänkii. Myöhemmin sitten se vähän niinku ehkä… hiipuu - jos on pienenä syntyny keskone ni monesti se on se kolmostason ehkä joku vahva kakkostason hoitaja joka siihen tullee sit omaksi hoitajaksi ja niitä on neljä kappaletta.. - sitten loppuvaiheessa kun lapsi onkii niinku ei enää kolmostason potilas niin ni sitten omahoitajuus ei ennää toteudu - tarttee miettiä että onko niinku alkuhoidon omahoitajat erit kun ne loppuhoitajat vai mikä on se ratkasu”* *“No, hoitajien vaihtuvuus, ja sitten kun meillä on tasoittain ne hoitajat ja sen mukaan kun se lapsi voi jo paremmin niin ei pääse enää tehohoitaja ei pääse enää hoitamaan paremmin voivaa potilasta.”* *“jotenkin mä näkisin, että se omahoitaja olis tärkee. Mut toisaalta, jos omahoitaja ei oo saanut hoitaa sitä lasta niin siinäkin on vaikee viikkokeskustella sitä lapsesta. Semmosta siitä ei tuu semmosta välttämättä kunnollista, mutta sitten jos joku on hoitanut sitä lasta niin siihen tulee se tatsi”*	Omahoitaja on luotettava, helpompi puhua vaikeistakin asioita Perheet kaipaavat omahoitajia, joiden kanssa hoitosuhde on erilainen Omahoitajan rooli vanhempien ohjauksessa on merkittävä Omahoitajuus ei toteudu kaikkien kohdalla Myös pienet keskusteluhetket omahoidettavan perheen kanssa nähdään merkityksellisinä Harvemmin perheen kanssa työskennellyt vuorohoitaja tukee perhettä heidän lähtökohdistaan kunnioittaen omahoitajan tekemää työtä Välillä perheet kysyvät miksi heillä ei ole omahoitajia Kokeneet hoitajat eivät pääse omahoitajina hoitamaan pientä keskosta lähellä kotiutumista osaston resurssien vuoksi Omahoitajuus hiipuu perheen kotiutumisvalmiuksien lisääntyessä Perheet saattavat kysyä, miksi omahoitaja on muissa työtehtävissä Ratkaisuksi omahoitajuuteen pohdittu, olisiko hyvä olla alkuhoidossa ja loppujaksolla eri hoitajat	**Named nurse system** ***Main points:*** *The role is seen significant* *Not systematic with all families* *Named nurses rarely discharged their "named" preemies*	**Support systems**	**Supportive NICU environment**